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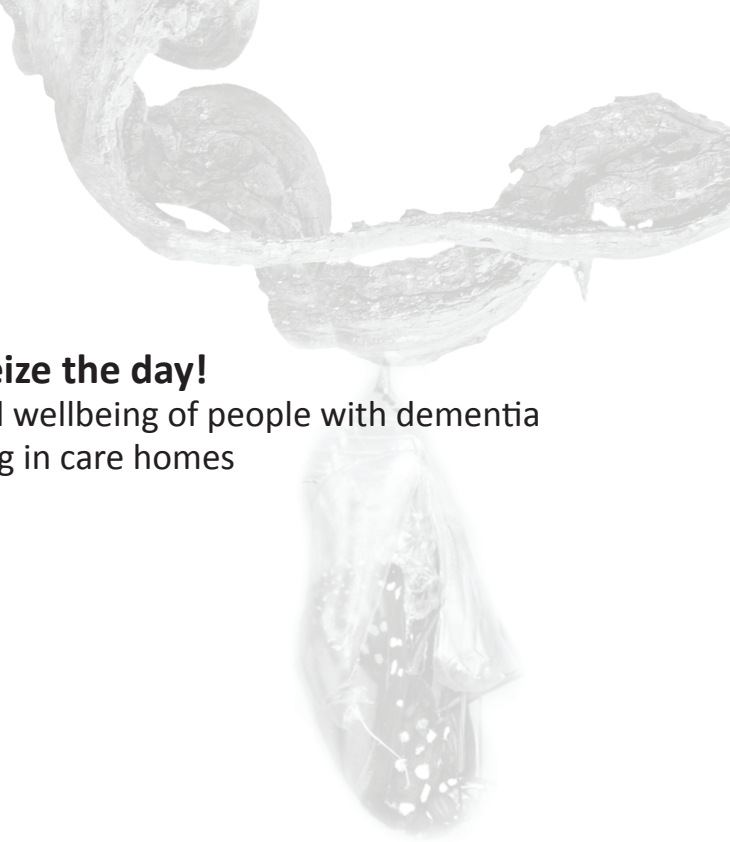

Seize the day!

Activity involvement and wellbeing of people with dementia living in care homes

Dieneke Smit

Colofon

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Seize the day!

Chapter 1 – General introduction

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1. Aim of this thesis

What comes to mind when thinking of spending an average day on a nursing home unit for people with dementia? Many people would picture a place where a group of ailing residents sit in their chair, asleep or watching the time go by. The nursing home is described as a place of boredom, leaving residents unoccupied for the best part of the day[1,2,3].

In recent years however, a transition towards a more stimulating environment is taking place. Care homes increasingly try to create a homelike atmosphere, thereby hoping to make their residents feel more at home and expose them to the stimuli of normal life[4]. Small-scale group living homes have been built, resembling a home from home as much as possible. In addition, large dementia care wards have been reorganized into smaller, more home-like living rooms. Providing care to smaller resident groups has enabled staff to become better acquainted with the people they care for. Furthermore, the role that family plays in the care for their relative has been given more room in this care concept. And bringing a pet when moving to a care home, has become common practice. With these developments, care organizations aim to focus on maintaining, or even improving, quality of life for their residents[5,6].

But is it realistic to think that the quality of life of residents with dementia can be preserved by a more stimulating physical environment, when the disease causes residents to steadily decline? Literature consistently finds disease-related factors (namely behavioural symptoms, depression and comorbidity) to be the strongest predictors of a resident's quality of life[7,8,9]. Despite the efforts to make residents with dementia feel more at home in care homes, the influence of the physical environment on quality of life seems limited[10,11,12].

The Healthy Aging model of the World Health Organization, states that the (care) environment has a vital role in compensating for losses that are experienced during life. Wellbeing is not the outcome of a person's losses, but that of the functional ability that someone experiences as a result of the compensation of these losses by the environment. In other words, even with substantial physical or cognitive limitations, someone's functional ability – and thus the level of wellbeing he or she experiences – can be maintained with the right environmental support. Naturally, the quality of the physical environment is important for someone's functional ability. But the social care environment, aimed at fulfilling psychological needs like meaning, autonomy, identity, enjoyment, security and relationships, is just as vital[13]. There is increasing awareness that daily occupation and involvement in activities might be an important way to address these psychological needs of people with dementia via the care environment[14,15,16]. Studies on activity programs have found positive effects on wellbeing and quality of life among people with dementia, such as positive mood, and elevated attention[17,18,19,20,21]. However, most results are based on small study samples or explorative research.

Based on the knowledge that researchers consistently find a lack of stimulation in care homes for people with dementia[2,3,22,23], while activity involvement and daily occupation can be of great value to increase their wellbeing, the aim of this thesis is twofold. First, we aim to obtain more insight into the relationship between activity involvement and occupation on the one hand, and the quality of life and wellbeing of people with dementia living in care homes on the other. Second, the impact of socio-demographic and disease-related characteristics, as well as that of various

aspects of the dementia care home environment on the residents' activity involvement and occupation are studied.
In the following paragraphs, further background information is provided on the dementia syndrome, the nursing home environment, the concepts of quality of life and wellbeing, the Healthy Aging model, and the need for occupation and activity involvement amongst care home residents with dementia. The relevance of this study is further explained and the research questions are presented. Finally, the outline of the thesis is described.

1.1 Dementia: a global health priority

Dementia is a progressive syndrome that causes severe cognitive deterioration, including memory loss, loss of comprehension, and loss of the ability to perform everyday activities. The dementia syndrome is caused by a variety of brain diseases of which Alzheimer's disease, vascular dementia and dementia with Lewy bodies are the most prevalent[24]. The occurrence rate of dementia is strongly related to higher age. It is estimated that 40% of people aged 90 or over have a type of dementia[25].
With the rising life expectancy especially in low and middle, but also in high income countries, the number of people with dementia is increasing rapidly. It was estimated that in 2015, there were 46.8 million people worldwide living with dementia. This number is expected to almost double every 20 years, leading to 74.7 million people with dementia in 2030, and 131.5 million in 2050[26]. Combined with the development that older people also constitute an increasing proportion of the total population, this places an enormous burden on society in terms of health care costs, and informal and formal care provision.
Despite the extensive investigation of various therapies, and although the development of treatments is an intergovernmentally agreed global health priority, no treatments are available yet to cure or alter the course of dementia[27]. Researchers are hopeful that in the coming years, a cure will be found, at least for some types of dementia[28].
The course of dementia is different for the various underlying brain diseases, and also varies between individuals. For Alzheimer's disease, accounting for 50 to 70 percent of the dementia syndrome, the average course is 4 to 8 years after receiving the diagnosis. Yet some Alzheimer patients can live up to 20 years following diagnosis[29]. Most people with dementia live at home. After receiving a diagnosis, people with dementia are often well able to live a good life for several years, often with increasing support from their environment. This support generally consists of help from family caregivers, supplemented with formal home care, or by attending a day centre in a later stage of the disease. Technological aids can also provide assistance. When people with dementia need almost 24-hour surveillance and help in all activities of daily living, a care home can be a better alternative to staying at home. An example is when living at home becomes unsafe because someone starts to wander outside, while not being able to find the way home; or when there is no family network to support the person with dementia, or the primary family caregiver becomes burned out by the care for his or her relative. It is estimated that in high income countries, one third to one half of people with dementia reside in care homes[30]. This number is much lower in low income countries, at an estimated 6%.

1.2 Transformation of the care home environment

Nursing home care[i] for people with dementia has been transformed enormously in recent

[i] Traditionally the term 'nursing home care' is used to address the care that is provided to people who reside in care homes because they need 24-hour care. However, we try to avoid this term in this thesis because today, this type of care is provided in various care facilities, varying from small-scale group living homes and special care units in homes for the aged, to the traditional large-scale nursing home.

decades. Until the 1970's, care professionals spoke of 'demented patients', from a medical perspective. From the 1980's on, it was increasingly recognized that as long as there was no cure for dementia, a stronger emphasis should be placed on the psychological needs of people with dementia. Instead of demented patients, professionals spoke of 'people with dementia'[31].

Thereafter, care professionals started to speak of 'people living with dementia', recognising the fact that people with dementia can still live a good life, when they are appropriately supported by their environment. There was increasing awareness that the physical care environment could influence residents' wellbeing and even their functioning, by creating a home-like, recognizable environment[4]. These insights resulted in the rise of various types of small-scale group living home facilities in several high income countries. Common features include small groups of 5-9 residents that live together, the home-like interior decoration of the care homes (preferably with the residents' own furniture), and avoidance of clinic-like features like long corridors[32]. In The Netherlands, this concept has been widely embraced. Whereas the first small-scale group living home facility was built in 1989, in 2017, it is estimated that 20 to 30 percent of the care homes for people with dementia have a group living home character in the Netherlands[33].

There were high expectations of the effect of Dutch group living home care on the wellbeing of residents. However, research conducted by separate research groups, did not generate convincing results pointing at a higher quality of life of group living home care residents as compared to residents of traditional nursing home facilities [10,11,12]. This led to the insight that altering the physical environment does not necessarily generate high quality care as provided by care staff[34].

Quality of life might best be maintained with a wellbeing-oriented and individualized care approach.

1.3 Quality of life and wellbeing as central goals in dementia care

In high income countries, improving or maximizing the quality of life and wellbeing of residents is currently perceived as the central goal of nursing home care. Illustrated by the continuous attempts to specify quality of life and wellbeing, there is still no consensus on how these outcomes should be defined and operationalized[35,36].

The most influential description of quality of life and wellbeing for people with dementia, however, originates from the work of Lawton dating from 1983[37], 1991[38] and 1994[14]. Lawton defined *quality of life* as 'the evaluation - both by subjective and social-normative criteria - of the behavioral and environmental situation of the person. According to Lawton, quality of life constitutes of four domains: the objectively determined domains of 1) a person's behavioral competence (or health status) and 2) the environment, and the subjective domains of 3) perceived quality of life (the evaluation of health and environmental aspects), and 4) the subjective *psychological wellbeing*. Particularly in people with diseases like dementia, psychological wellbeing should be perceived as the most important component of quality of life[14,35]. Lawton wrote that 'the focus on psychological wellbeing helps us to keep viewing people with dementia as human beings with continuing likes and dislikes. It makes the efforts made in long term care provision worthwhile, despite their ongoing deterioration of cognitive and functional capacities'[14].

Following this theory, the concept of psychological wellbeing for people with dementia has been studied extensively, resulting in various – both overlapping

and different – descriptions[36,39]. Examples are: positive and negative affect, mood, happiness, enjoyment, satisfaction, self-acceptance, self-esteem, dignity, individuality and spiritual wellbeing[14,40,41,42].

1.4 The World Health Organization's model of Healthy Aging

In 2015, the World Health Organization (WHO) published the World Report on Ageing and Health describing a new model of 'Healthy Aging'[13]. Healthy Aging is defined as 'the process of developing and maintaining *functional ability* that enables wellbeing in old age', so that people can continue to be and to do what they have reason to value in life. In the WHO's Healthy Aging model, wellbeing is considered in the broadest sense and includes domains such as happiness, satisfaction and fulfilment, comparable to the concept of psychological wellbeing as described above. Diseases like depression, geriatric syndromes like dementia, comorbidity and other health related factors do not determine the wellbeing of older people, but the extent to which the reduction in capacities as a result of these diseases are, or are not, compensated by the environment.

With the concept of Healthy Aging, the World Health Organization has called upon the care environment to take responsibility for the wellbeing of care home residents with dementia. People with dementia are entitled to have access to a supportive physical environment, but to achieve psychological wellbeing, their basic human rights and needs have to be addressed. It is rudimentary to acknowledge that the person living in a care home still has a life. The care environment must actively seek to identify the resident's individual needs, and do everything within its power to fulfil these needs.

Studies on the subjective needs of individuals with dementia in long term care revealed various aspects of life that were viewed as necessities, such as the need for security, autonomy, privacy, identity, meaningful activities or daily occupation, meaningful relationships, and love[15,43,44].

1.5 The impact of occupation and activity involvement on functional ability and wellbeing

Many of the psychological needs of people with dementia can be addressed by engagement in daily occupation and activities[3,14,15,41,45,46,47,48,49]. In this thesis, both the involvement in activities, and daily occupation are studied.

We have defined *Involvement in activities* as the engagement in recreational and leisure activities. Examples are fitness classes, painting, group conversations, singing, and board games.

Daily occupation for people with dementia entails more than activity involvement. It has been described as 'involvement in life in a way that is personally significant'[15]. Occupation refers to the recreational activities mentioned above, but it can also involve having a meal, receiving physical care, taking interest in a stuffed animal, watering flowers, helping others, social conversation, and so on[50].

The literature that is available on the relationship between activities and daily occupation on the one hand, and quality of life or wellbeing on the other, primarily consists of small study samples, phenomenological research, or descriptions of specific activity programs. The findings report several positive outcomes of activities and occupation, such as more positive affect, less depressive symptoms, elevated interest and alertness, less boredom, higher nutrition intake and decreased use of psychotropic medications [e.g. 17-21,51,52]. In particular, activities and types of occupation that are tailored to the individual needs and preferences are expected to contribute to quality of life and wellbeing[53]. The lack of activity involvement or occupation on the other hand, is related to several adverse outcomes: a loss of physical function, social isolation, neuropsychiatric symptoms and poor quality of life[54]. It is even suggested that the lack of occupation results in what is called *excess disability*: disability that is not the pure result of

the dementia process, but is caused by additional atrophy of skills and functional capacities due to an environment that does not support the needs of people with dementia (the *malignant* environment)[55].

Yet, despite the assumed potential of activity involvement and occupation, dementia care homes seem to struggle to reach an appropriate activity level amongst their residents. Literature consistently states that the level of engagement is extremely low in this resident group[3,56,57]. As recently as 2014, residents of 19 dementia units were found to be inactive (defined as sleeping, doing nothing, or watching TV) for 48 to 78 percent of the observed timeframes[23].

1.6 Potential explanations for the lack of occupation and activity involvement

Why do care homes fail to address the need for occupation and activity involvement of their residents with dementia – notwithstanding the WHO's model of Healthy Aging and the focus on wellbeing in dementia care?

A first explanation may be that care professionals are still not aware of the potential impact of activity involvement and daily occupation on a resident's quality of life and wellbeing. Engaging residents in activities might seem of secondary value for the wellbeing of residents. Care staff – mainly registered nurses or certified nursing assistants – are primarily focused on the provision of basic physical care, a clean environment and comfort[45,58] especially for people with severe dementia. These are also the things they have been taught, and what staff are often judged upon by family caregivers, colleagues and care managers. While physical care, a clean environment and comfort are essential to compensate for one's physical losses, other (emotional and psychological) needs are overlooked that also have to be fulfilled to experience optimal wellbeing – as addressed by the Healthy Aging model[13].

Besides not recognizing the potential of activity involvement , staff may not know how to involve residents in activities. Care staff are not educated in how to keep residents involved in daily occupation that they value, especially those with more severe dementia[59]. Activity provision or engaging residents in daily occupation, is often perceived as the task of specialists like recreational or activity workers, both by care staff and care managers.

Furthermore, the interventions and activity programs that are studied in literature[17-20], seem to be too complex to be implemented by the direct care staff. Care managers must invest in their care staff to put activity involvement on the agenda, but in times of a growing societal burden of disease caused by an aging population, leading to staff shortages and financial cutbacks, this receives low priority.

Moreover, it is unclear whether 'regular activity involvement' or daily occupation affects wellbeing or quality of life too, also in the long run. Evidence of this relationship will further encourage care home managers to facilitate activity provision on their care sites.

Finally, policy makers in the field of long term dementia care might not be convinced by the literature that is available on activities and wellbeing, that often comes from small study samples or entails more phenomenological research on the concept of meaningful activities than generating concrete implications for care practice.

1.7 The problem placed in context: Relevance of this study

In summary, the recognition of the need for a home-like and familiar environment to improve the wellbeing of care home residents with dementia, has led to a rapid transition towards group living home care in a relatively short time period in the Netherlands. However, the need for activity involvement and daily occupation that has also been expressed for some time, seemed to be ignored until recently.

In its most recent care policy, the Dutch government has placed considerable emphasis on the need for daily occupation and activity involvement for residents with dementia. Just as with the transition towards group living care, a stimulating policy has been initiated to enlarge the activity provision in long term care homes[60]. Care homes receive substantial fees when they stimulate activity provision by their care staff from 2016-2020[61]. On the other hand, in 2017, their regular annual incomes were substantially lowered in relation to the rising spending (predominately caused by increased salaries in keeping with the altered collective labour agreement of 2016-2018[62]). From 2018 on, substantially more financial means will be made available by the Dutch government for the nursing home care sector[63] as a response to the large discontent with the quality of nursing home care that is currently experienced by the general public in the Netherlands.

The Dutch dementia care homes approach the challenge of increasing activity provision for their residents in different ways. Some attract extra recreational workers to provide activities in addition to the regular care. Others start programs with neighbours and volunteers. Technical aids may also be purchased for increasing opportunities to engage in activities. Or care homes invest in the education of their staff to integrate activity provision into regular care[64]. The question arises whether the efforts for increasing activity involvement are sustainable when funding stops and when the available workforce further decreases.

There is also an important global development regarding this topic. In most high income countries, people with dementia enter care homes at a later stage of their disease in comparison to a decade ago, as a consequence of 'aging in place policies'. These policies are meant to enable older people to stay in their own homes for as long as possible, even when they increasingly need care[65,66]. Since higher care demands were found to be related to lower activity involvement[67,68], knowledge is desired on whether the need for occupation decreases as suggested by some[69], or that it is necessary to equip care homes with information on how to increase activity provision for this resident group.

1.8 Research questions

This thesis tries to address these issues by answering the following research questions:

1. To what extent is the involvement in activities and daily occupation related to the quality of life and wellbeing of people with dementia living in care homes? Is this relationship different for people at different stages of dementia? *(presented in Figure 1.1)*

2. Which characteristics concerning residents, environment, and staff of the care home influence their activity involvement and daily occupation? *(presented in Figure 1.2)*

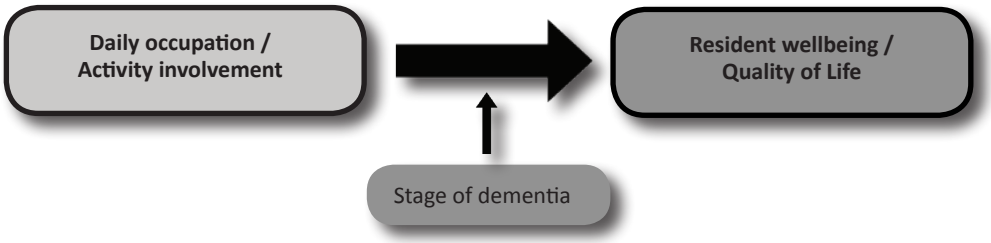

Figure 1.1 relationships studied with research question 1

Figure 1.2 relationships studied with research question 2

2. Research methods

Various methods were used to answer the research questions that are described above. Data from three measurement cycles of the Living Arrangements for people with Dementia (LAD-) study were used. The LAD-study was initiated in 2008, and designed to monitor the developments in Dutch nursing home care for people with dementia and the consequences of environmental and organizational characteristics for residents' and staff's wellbeing.

The following data were used to study our research questions:

a) Measurement cycle 2008-9 of the LAD-study: Cross-sectional data derived from 1,144 residents through observational questionnaires, representing 136 care homes *(research question 2)*

b) The in-depth study of the LAD-study performed in 2010: Dementia Care Mapping observations[70] performed by trained researchers on occupation and wellbeing of 57 residents and their care environment in a selection of 10 high and low quality care homes *(research question 1 and 2)*

c) Measurement cycle 2010-11 of the LAD-study: Cross-sectional data on organizational characteristics (derived from interviews with the care home management), staff characteristics (derived from 1,145 care staff members), family characteristics (derived from 888 family members) and resident characteristics and activity involvement (derived from 1,218 observational questionnaires), representing 139 care homes (*research 1 and question 2)*

d) A sub-study of measurement cycle 2013-14 of the LAD-study: Staff observations of residents they were primarily responsible for (n = 171) on occupation and wellbeing, representing 50 care homes *(research question*

When applicable, multilevel analyses were performed to study the potential relationships, to control for the clustered data of residents and organizational structure belonging to one care home.

3. Outline of the thesis

In **chapter 2**, the design of the first measurement cycle of the Living Arrangements for people with Dementia is described, as well as that of the in-depth study *(datasets a and b)*. Chapter 2 does not cover the following measurement cycles of the LAD-study, but the information collected in these cycles strongly resembles that of cycle 1. However, the participating care homes are partly the same, and partly different in the forthcoming measurement cycles. Specific differences in the data collection as compared to measurement cycle 1, if applicable, are described in detail in the separate chapters.

Chapter 3 describes the explorative study on the relationship between types of occupation and wellbeing, and the impact of the care environment on different types of occupation, using Dementia Care Mapping. In this study, both our research questions are addressed *(dataset b)*.

Chapters 4 and 5 focus on the relationship between involvement in activities or occupation, and wellbeing or quality of life *(research question 1)*. In **chapter 4**, the relationship between overall involvement in activities and quality of life is studied in a large resident sample by data from standardized questionnaires. Special attention is given to the relationship between activity involvement and wellbeing in people at different stages of dementia *(dataset c)*. In **chapter 5**, the involvement in different types of daily occupation and the relationship with wellbeing in people at different stages of dementia are described, based on observations of regular care staff *(dataset d).*

Chapters 6 and 7 address the relationship between environmental features of the care home and activity involvement *(research question 2)*. In **chapter 6**, the relationship between characteristics of small-scale group living home care and the involvement of residents in activities in general and activities that they preferred, are described. Also the different types of activities are studied *(dataset a)*. **Chapter 7** addresses the question which of the various factors that were suggested to influence activity involvement in previous literature, are most important. 40 characteristics of the care environment are studied *(dataset c)*.

We reflect upon the results and research methods as described in the earlier chapters in **chapter 8**, the general discussion of this thesis. Implications for further research, care practice and policy are outlined.

With this thesis, we hope to contribute to the further improvement of the care environment for people with dementia, by helping them to get the most out of their lives. ***Seize the day!***

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Seize the day!

Chapter 2 – Nursing home care for people with dementia and residents' quality of life, quality of care and staff well-being: Design of the Living Arrangements for people with Dementia (LAD-) study.

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Seize the day!

Abstract

Background: There is a growing attention for group living home care for people with dementia around the world. Characteristics of group living home care are not only found in archetypical houses for people with dementia, but are increasingly integrated in a broad variety of living arrangements. There is limited information available on how characteristics of the organization of care and especially group living home care and staff ratio contribute to care staff wellbeing, quality of care and residents' quality of life. Furthermore, it is unknown what the consequences of the increasingly small scale organization of care has for the amount of care staff required in 2030 when there will be much more older people with dementia.

Methods/Design: This manuscript describes the design of the 'Living Arrangements for people with Dementia study' (LAD-study). The aim of this study is to include living arrangements from every part of this spectrum, ranging from large scale nursing homes to small group living homes. The LAD-study exists of quantitative and qualitative research. Primary outcomes of the quantitative study are wellbeing of care staff, quality of care and quality of life of residents. Furthermore, data concerning staff ratio and characteristics of the living arrangements such as group living home characteristics are assessed. To get more in-depth insight into the barriers and facilitators in living arrangements for people with dementia to provide good care, focus groups and Dementia Care Mapping are carried out.

Discussion: Results of this study are important for policymakers, directors and staff of living arrangements providing nursing home care to people with dementia and essential for the development of methods to improve quality of care, residents' and staff well-being. Data collection will be repeated every two years, to generate knowledge on the results of changing policies in this field.

Background

There is a growing attention for group living home care for people with dementia around the world. In the Netherlands, at the moment 25% of the residents with dementia who receive nursing home care lives in group living homes [1]. Group living home care refers to a concept of care in which nursing home care is organized in a home-like environment where residents live together in small groups. Personal care is integrated into daily routines, so that daily life is as 'normal' as possible. This means that health care staff performs care tasks as well as domestic tasks, such as cooking and cleaning [2]. In general, it is believed that group living home care is beneficial for the physical and psychosocial wellbeing of the residents [3].

Initially, group living homes were developed according to the ideals of the pioneers in this field who stated that a group living home is located in an archetypical house where a maximum of six residents live together [2]. Nowadays, several types of living arrangements providing group living home care appear. Group living home care is not only provided in archetypical houses in regular neighborhoods, but also in homes on the site of a nursing home or assisted livings and within larger scale nursing homes. The number of residents per group is no longer limited to a maximum of six. In conclusion, characteristics of group living home care are increasingly integrated – at least to some extent - in all types of living arrangements

for people with dementia.

Although it is generally believed that group living home care is better for the well-being of the residents and caregivers, worries exist that group living home care is more expensive and that more staff is needed in arrangements in which many characteristics of group living home care are integrated. These worries are based on the dejuvenation in combination with the graying of the population. The prevalence of dementia will increase in the next decades [4], while the labor force will shrink in the same period of time [5]. Around 21% (N=50.000) of all people with dementia in the Netherlands is living in a nursing home care setting [6]. It is estimated that in 2030 there would be 35 potential employees for one person with dementia, compared to 55 at this time [7]. Probably this is even an underestimation because the impact of aging of the population on the labor force was less obvious at the time these estimations were made.

Regarding the implementation of group living home care and the dejuvenation and graying of the population, it is increasingly important to get insight in what contributes to job satisfaction and burnout, sickn leave and turnover of care staff in living arrangements for people with dementia. In addition, insight in the consequences of group living home care in terms of the number of staff needed is required.

The focus of research in this field has mainly been on a comparison of quality of life of residents and staff wellbeing in two or three types of arrangements [8-17]. Two studies focusing on the effect of small scale facilities in the Netherlands compared to large scale nursing homes show modest positive results of small scale facilities on some aspects of quality of life of residents with dementia, but no differences are found for overall quality of life [10,18]. Furthermore, these previous studies show that staff working in group living homes experience more job satisfaction, a higher motivation and less burnout than staff working in regular nursing homes [9,18]. There is limited knowledge on the effect of the amount of group living home care characteristics provided in all - larger or smaller - types of nursing homes, staff ratio and other characteristics of living arrangements on quality of life of residents, quality of care and staff wellbeing.

Two studies in the United States do focus on the relationship between characteristics of the organization of care in long-term care facilities and outcomes for residents and staff [19,20]. The Collaborative Studies of Long-Term Care shows that depression is more common for participants in for-profit nursing homes than for those in other homes (nonprofit homes and residential care/ assisted living) [21]. The Maryland Long-Term Care Project shows a beneficial impact of residents' privacy and a negative impact of staff turnover on resident infection and hospitalization for infection [19]. These results support the hypothesis that characteristics of the organization of care - such as care concept or philosophy of care and staff ratio - are important for outcomes related to residents and staff in nursing homes.

Aim and main research questions

In order to get insight into the relationship between the characteristics of living arrangements for people with dementia and residents' quality of life, quality of care and staff well-being, we designed the 'Living Arrangements for people with Dementia study' (LAD-study). Several characteristics of living arrangements are studied with special attention for the impact of group living home care characteristics and staff ratio. This article describes the methods of the first measurement cycle of LAD-study. The three main research questions are:

1. What is the effect of group living home care characteristics and staff ratio on quality of life of residents, quality of care and wellbeing of care staff?
2. What is the effect of the variety in care supply for people with dementia and the growing portion of group living home care on the amount of care staff required 20 years from now?
3. What are barriers and facilitators in living arrangements for people with dementia to provide good care?

Methods

Design

The LAD-study is an ongoing monitor which is intended to be repeated every two years. Here we describe the design of the first measurement cycle of the LAD-study which comprises a quantitative and a qualitative study. In the quantitative study staff ratio, characteristics of the organization of care, wellbeing of care staff, quality of care and quality of life of residents are measured (research question 1 & 2).
In the qualitative study, data collection via focus groups and structured observations according to the Dementia Care Mapping (DCM) method in a selection of the participating living arrangements are carried out (research question 3). The methods concerning the quantitative and qualitative study are described separately.

Ethical considerations

Data of people with dementia are collected via observation by the health care staff. Therefore the medical-ethics committee METiGG stated that the 'Medical Research Involving Human Subjects Act' was not applicable and that the study did not need approval. Registered legal representatives of the residents to be observed with Dementia Care Mapping received a letter with information on this method.

Methods quantitative study

Study population and recruitment

All 734 living arrangements that provided nursing home care for people with dementia in the Netherlands were addressed to participate in the first data collection of the LAD-study. In the Netherlands, nursing home care for people with a primary diagnosis of dementia is organized on wards which exclusively provide care to people with dementia. These wards are comparable to special care units in the United States, however, they vary to a great extent. The aim of this study was to include 150 living arrangements from every part of this spectrum. For this purpose, we distinguished five types of living arrangements: traditional large scale nursing homes, nursing home wards in a home for the aged, large nursing home where group living home care is provided, group living homes nearby the mother facility

Table 2.1: Data collection: measures and operationalization of quantitative study

Measure	**Operationalization**
Living arrangement characteristics	
Number of residents in living arrangement	Number of residents
Number of residents per living room	Number of residents
Time of existence of living arrangement	Months
Group living home care characteristics	Group living home care questionnaire [2]
Inclusion criteria at admission	Type and number of criteria
Transferring criteria	Type and number of criteria
Education for care staff	Type of education
Technological aids in care and housing	Type and number of aids
Resident characteristics	
Age	Years
Gender	Male or female
Length of stay	Number of months
Visits from family or friends	Frequency
Stage of dementia	FAST [26]
ADL-dependency	KATZ [28]
Neuropsychiatric symptoms	NPI-Q [41]
Referral (reimbursement)	Euro's
Care staff characteristics	
Age	Years
Gender	Male or female
Origin	Dutch or other
Educational level	Type of education and level (e.g. level 1 - 5)
Working hours	Hours per week
Employment in profession	Years
Length of service	Years
Staff ratio	
Direct caregiver	Hours per week per resident
Educational level	Hours per week per educational level per resident
Facilitating services	Fulltime equivalent
Professional services	Fulltime equivalent
Sick leave	Percentage
Care staff wellbeing	
Primary outcomes	
Job satisfaction	Subscale job satisfaction from LQWQ [32]
Burnout complaints	UBOS [33-35]
Secondary outcome	
Workload	Subscale from LQWQ [32]
Autonomy	Subscale from LQWQ [32]
Social support	Subscale from LQWQ [32]
Quality of care	
Physical restraints	Type and number of times used per resident
Psychotropic drugs	Type and number of times used per resident
Client satisfaction	CQ-index [25]
Approach to dementia	ADQ [36]
Involvement in activities	Subscale from MDS: RAI [24]
Quality of life	
Quality of life	QUALIDEM [22,23]
Pain	Subscale from MDS: RAI [24]

and stand-alone group living homes in the community. Our aim was to select 30 living arrangements in each of these 5 categories. All living arrangements participating in this study are non-private facilities, receiving reimbursement dependent on the referral status of the resident: a regular indication or a higher indication based on a higher level of behavioral problems.
A brochure with information on the study was sent to the director of the living arrangements and a short inventory was attached. This inventory focused on some basic organizational characteristics of the arrangement, for example the amount of residents they are caring for in total and per ward. In addition, they were asked in which of the 5 types of living arrangements they would classify the living arrangement and if they were willing to participate in our study. In case there were more than 30 arrangements in a same category willing to participate, 30 arrangements were randomly selected.
In every participating living arrangement 12 residents and 15 health care staff were randomly selected to participate in the study. In this study, we focused on health care staff (i.e. nursing assistants, certified nursing assistants and registered nurses) working on a permanent basis. Temporary staff and student-nurses were excluded.

Measures
Table 2.1 provides an overview of all variables that are investigated in this study: characteristics of living arrangements, residents, and care staff and outcomes of staff ratio, care staff wellbeing, quality of care and quality of life of residents.

Living arrangements
The following facility demographics are collected: facility type, time of existence, number of residents in the living arrangement in total and on the wards, whether inclusion criteria are taken into account at time of the admission of a new resident, provided education for care staff, sick leave, technological aids in care and housing and group living home characteristics. Group living home characteristics are assessed using a questionnaire we developed in a previous study based on a Concept Map concerning the ideals of group living home care [2].
Furthermore, data are collected on staff ratio: the amount of direct care staff and their level of education, the ratio of other professionals such as physicians and paramedics and the amount of facilitating services such as domestic services .
Finally, registrations on the use of physical restraints and psychotropic drugs are asked to get insight in the quality of care of the arrangements.

Residents
Quality of life and involvement in activities are the primary outcomes for the residents.
Quality of life of residents is examined with the Qualidem [22,23]. This scale is especially developed for residents with dementia in nursing home facilities. It is a multi-dimensional scale which assesses nine dimensions of quality of life in dementia: Care Relationship (7 items), Positive Affect (6 items), Negative Affect (3 items), Restless Tense Behaviour (3 items), Positive Self Image (3 items), Social Relations (6 items), Social Isolation (3 items), Feeling at Home (4 items) and Having Something to Do (2 items). In addition to the Qualidem, the presence of pain is

observed as an indicator of quality of life using two questions of the long term care version of the Minimum Data Set (MDS) of the Resident Assessment Instrument [24].
Residents' involvement in activities is measured with the subscale Activity Pursuit of the MDS [24]. Residents' preferences on and involvement in the last three days in 20 activities are assessed using a six-point scale. Furthermore, the amount of time residents are involved in activities or are sleeping during the day is measured.
As an indicator of quality of care, client satisfaction is assessed by asking the report of the Consumer Quality Index (CQ-index) [25], a measurement of client satisfaction which every nursing home facility must assess once every two years since 2007 in the Netherlands. For people with dementia, the informal caregiver fills in this questionnaire.
The following measures are used to control for the functioning of residents. The severity or stage of dementia is measured with the Functional Assessment Staging (FAST) questionnaire [26,27], consisting of sixteen questions. The FAST Stage is the highest consecutive level of disability of the person with dementia. A higher score on the FAST procedure indicates a more advanced stage of dementia.
Assistance needed with Activities of Daily Life is measured by using the Katz index of ADL [28]. The index exists of six items, a higher score on the Katz index of ADL means more dependence in ADL.
Behavioral problems were measured with the abridged (paper-and-pencil) version of the Neuropsychiatric Inventory [29]. Each of the twelve items of this scale measures a psychiatric symptom. A higher score indicates greater symptomatology.
Finally, demographic variables age, gender, length of stay and frequency of family visits are assessed.

Care staff
Job satisfaction, intention to leave and burnout complaints are the primary outcomes for care staff. Additionally, the job characteristics of the Job-Demand-Control-Support model [30] and the care staff approach to dementia are measured. Job satisfaction, intention to leave and the job characteristics – job demands, job control and social support [31]- are measured with the Leiden Quality of Work Questionnaire [32]. This questionnaire measures 11 job characteristics. The five subscales concerning the JDCS model are used in this study: the Job Satisfaction subscale (6 items), measuring job satisfaction and intention to leave, the Work and Time Pressure (5 items) and Decision Authority subscale (4 items) respectively measuring job demands and job control and the Social Support Supervisor subscale (4 items) and the Social Support Co-workers subscale (4 items) measuring social support.
The outcome variable burnout is measured with the Dutch version of the Maslach Burnout Inventory [33], the Utrecht Burnout Scale – C [34,35]. This scale measures three components of burnout: emotional exhaustion (8 items), depersonalization (5 items) and decreased personal accomplishment (7 items). Higher scores suggest more burnout complaints.
Person centered approach of people with dementia is measured using a Dutch translation of the Approach to Dementia Questionnaire [36]. This questionnaire contains nineteen attitudinal items about people with dementia. A higher score indicates a more person-centered attitude toward people with dementia.
Finally, demographic variables and variables on care staff's employment in the living arrangement are recorded.

Procedure
Seventeen research assistants have been extensively trained by the research team to collect the data for the first measurement cycle of the LAD-study.
The facility demographics and staff ratio of the facilitating services and other professionals are provided by interviewing the manager. The interviews are audio recorded.
To calculate the staff ratio of care staff, timetables of the living arrangements are used. The CQ-index is asked from the manager to get insight in client satisfaction. Additionally, registrations of the use of physical restraints and psychotropic drugs are required from the nursing home physician.
Outcomes regarding members of the care staff are based on self-report questionnaires.
A registered nurse (RN) or certified nursing assistant (CNA) who is most involved with a selected resident is asked to fill in the questionnaire measuring residents' characteristics, such as their quality of life. Care staff and residents are randomly selected by the research assistants.

Statistical analysis
Descriptive statistics areused to describe characteristics of participating living arrangements, residents and care staff. Regression analyses are used to study the effects of group living home care characteristics and staff ratio on outcomes of living arrangements. For care staff and resident outcomes multilevel regression analyses are applied.

Methods qualitative study
Study population and recruitment
The qualitative part of this study provides more in-depth insight into facilitators and barriers for success in living arrangements for people with dementia. Using a selection of the quantitative data of the LAD-study, all living arrangements are scored on the wellbeing of the care staff, the quality of care, the quality of life and the amount of health care staff. The scores on these four outcomes are transformed to percentiles and added resulting in a 'total score of success'. For every type of living arrangement, arrangements with the highest and the lowest scores are selected. The measures of the quantitative study and the scores on which these four outcomes are based are indicated in table 2.2. In total ten living arrangements are included in this qualitative study.
The selected living arrangements are asked if they are willing to participate in the qualitative part of the LAD-study. If not, the living arrangement with the second highest or lowest score are selected.

Focus groups
The first part of the qualitative study consists of focus groups from three perspectives. Focus groups are group discussions organized to explore people's views and experiences concerning a specific set of issue's [43]. One focus group exists of managers and healthcare professionals, one of members of the care staff and one of family members of the residents. In all three focus groups the same questions are asked focusing on what their opinion is on points of success and improvement of the living arrangements and how care staff, residents, family members, volunteers,

Table 2.2: Selection criteria for qualitative study

Selection criteria	**Operationalization**
Efficiency staff ratio	
Direct caregiver	Hours per week per resident
Educational level	Hours per week per educational level per resident
Facilitating services	Fulltime equivalent
Referral (reimbursement)	Euro's
Quality of care	
Physical restraints	Type and number of times used per resident
Psychotropic drugs	Type and number of times used per resident
Approach to dementia	ADQ [36]
Care staff wellbeing	
Job satisfaction	Subscale job satisfaction from LQWQ [42]
Burnout complaints	UBOS [33-35]
Quality of life of residents	
Quality of life	QUALIDEM [22,23]
Pain	Subscale from MDS: RAI [24]

management, finances, vision, policy and environment contribute to this. The focus groups are conducted by a conversation leader and an assistant, taped and typed up literally.
The conversation leader and assistant fill in a form after every focus group. The analysis form consists of the following questions: What did this focus group contribute to answering the research question? What got your attention? What was your own role during the conversation? What are points of attention for the next time? The focus groups reports are critically read by researchers of the research team. The reports are imported in MAXQDA and coded on points of success and improvement and suggested explanations. The texts are coded by two researchers and discussed until consensus is reached. The method of constant comparison is used in which case fragments of all participating living arrangements with the same code are compared on agreement and differences.

Dementia Care Mapping

The second part of the qualitative study consists of structured observations using the Dementia Care Mapping (DCM) method. DCM is a method developed by the Bradford Dementia Group [37] and is based on Kitwood's psychosocial theories of dementia [38]. Dementia Care Mapping is a structured method to observe people with dementia and their formal caregivers to evaluate the quality of care from the point of view of people with dementia. Data collection involves the coding of behavior and wellbeing or ill-being of the residents every five minutes, ranging from very negative (-5) to very positive (+5). Furthermore, their involvement in activities are recorded for several behavior categories. When members of the care staff are present in the room the quality of their interactions with residents are scored ranging from highly detracting to highly enhancing behavior concerning the five psychological needs as described by Kitwood [39].
In the selected living arrangements a trained mapper observes six residents in one living room during two periods of three hours. When the mapper observes in a living room where more than six residents are staying the mapper and leader make a varied selection of residents based on

gender, stage of dementia and amount of disruptive behavior. Only residents that are living in the living arrangement for more than one month are observed.
In addition, the mapper assesses a number of environmental features , such as environmental cues and a home-like décor. The environmental category codes are based on the DCM-Environmental Category Codes (ECCs) [40].

Case report
For all ten cases a report on the facilitators and barriers of the living arrangements is written. These reports are send to the living arrangements and are discussed (member check). Finally, the facilitators and barriers of all cases are compared for corresponding and differing factors.
Based on results of the case reports the most important facilitators and barriers for success in living arrangements for people with dementia are specified.

Discussion

In this paper we described the design of the Living Arrangements for people with Dementia study (LAD-study), in which 136 living arrangements for people with dementia participate in the first measurement cycle. The results of this study will add to the literature in a number of ways.
In stead of comparing group living homes with another type of living arrangement, we measure the extent of integration of group living home care in daily practice and staff ratio in a broad variety of facilities. Thus, we focus on the impact of group living home care characteristics and staff ratio on the satisfaction of care staff, quality of care and quality of life of residents. In addition, the combination of the quantitative and qualitative design of the LAD-study makes it possible to get in-depth information on facilitators and barriers of success in living arrangements for people with dementia. Finally, this study gives insight into the consequences of group living home care for people with dementia for the labor market of staff.
The information concerning the organization of care is important for national and local directors and staff of living arrangements for people with dementia providing nursing home care. This knowledge can be used for the development of methods to improve care for people with dementia. Finally, this information is essential for policymakers to decide which factors in nursing home care for people with dementia need special attention or needs to be stimulated. In addition to this first measurement, data collection will be repeated every two years, to generate knowledge on the results of changing policies in this field.

Competing interests
The authors declare that they have no competing interests.

Authors' contributions
BW drafted the manuscript and helped designing the study. DS and JdL helped draft this manuscript and helped designing the study. AMP designed and supervised the study and helped to draft this manuscript.

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Seize the day!

Chapter 3 – Wellbeing enhancing occupation and organizational and environmental contributors in long term dementia care facilities: an explorative study.

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Seize the day!

Abstract

Background Occupation remains an unmet need in long term dementia care. To increase residents' occupation, knowledge on types of occupation related to wellbeing, and organizational and environmental characteristics encouraging involvement in these types of occupation, is indispensable.

Methods In this explorative study, Dementia Care Mapping was used to study involvement in different types of occupation and wellbeing among 57 residents of 10 dementia care facilities. For each type of occupation, mean experienced wellbeing was studied. Occupation types with high mean wellbeing scores were classified as 'wellbeing enhancing occupation'. Care facilities were ranked according to the mean time residents spent in types of wellbeing enhancing occupation. Using information on staff to resident ratio, individual space, and items of the Physical Environment Evaluation Component of Dementia Care Mapping, organizational and environmental characteristics of the facilities were compared to study their relationship with wellbeing enhancing occupation.

Results Reminiscence, leisure, expression, and vocational occupation had greatest potential to enhance wellbeing, but these types were seldom offered. Much variation existed in the extent to which wellbeing enhancing occupation was provided. Long-term care facilities that did so more frequently generally had a more homelike atmosphere, supported social interaction through the environment, and had no central activity program.

Conclusions This study suggests that it is possible to engage residents in wellbeing enhancing occupation, within current means of budget and staff. The physical environment and care organization might play a role, but the key factor seems to equip staff with skills to integrate enhancing occupation into care practice.

Introduction

Dementia has serious consequences for the quality of life of those who suffer from the syndrome, and for his or her network. Cognitive degeneration causes problems with communication, memory, planning and motor functioning. These problems can seriously affect the fulfillment of basic psychological human needs. One of these needs is occupation (Kitwood, 1997).

Occupation has been described as 'involvement in life in a way that is personally significant' (Kitwood, 1997), and 'that which we seize for our own personal possession, and which engages our time, attention and environment' (Perrin, May and Anderson, 2008). Occupation goes beyond pure involvement in recreational activities. It can involve work, leisure, and play, but also getting up, eating and drinking, receiving physical care, sexual stimulation, interest in objects, helping others, social conversation, and so on (Elliot, 2011). People with dementia become increasingly dependent on their environment to be occupied, since they lose skills to initiate activities and increasingly need visual or verbal prompting to start occupation (Cook, Fay and Rockwood, 2008). Especially in a long term care environment where their sick role and dependency are emphasized and where it is hard to exercise autonomy, occupation can be a challenge for people with dementia (Harmer and Orrell, 2008).

Research has shown however that residents with dementia still consider occupation to be important for their quality of life (Dröes *et al.*, 2006; Train *et al.*, 2005).

Moreover, several studies show that occupation can have beneficial effects on wellbeing of long term care residents with dementia. For example, involvement in scheduled recreational activities such as games or songs was found to increase residents' positive affect or 'happiness' during these activities (Schreiner *et al.*, 2005). A continuous activity program in which long term care residents were brought to a 'club area' to be engaged in various activities during the day, was found to improve behavioral problems, decrease the use of psychotropic medication, improve nutritional status and decrease social isolation (Vollicer *et al.*, 2006). In an intervention program called TimeSlips, where residents and staff constructed stories together once a week for one hour for 10 weeks, higher engagement and alertness were found in the intervention group compared to a control group, although the intervention group also expressed higher levels of anxiety and sadness (Fritsch *et al.*, 2009). The Enriching Opportunities Program, an activity based model of care where the capabilities and interests of residents are assessed and staff are trained to provide activities under supervision of a specialized staff member, led to an increase in wellbeing and diversity of activity (Brooker, Woolley and Lee, 2007). Lack of occupation on the other hand can result in boredom, apathy, disruptive behavior, loss of self-esteem, depression, social exclusion, and loneliness (Kolanowski, 2006).

But despite the fact that activity programming is evidently important to residents and is even mentioned in recent dementia care practice guidelines (e.g. SIGN, 2006; NICE SCIE, 2007; APA practice guideline, 2007), wide implementation in care practice seems to remain difficult as illustrated by recent studies in which occupation was still found to be a large unmet need amongst long term care residents with dementia (Orrell *et al*., 2008; Passos, Sequeira and Fernandes, 2012).

Several organizational and environmental factors may contribute to this problem. The most commonly used explanations for limited activity programs are limited resources in terms of staff and finances. Both care workers and family caregivers often express the need for additional staff to engage residents in meaningful occupation (Harmer and Orrell, 2008; Train *et al.*, 2005). Innes and Surr (2001) structurally observed active and inactive behavior of 76 residents with dementia over a total of 269 hours, and found no relationship between staff ratio and the engagement of residents in occupational activity.

Another important influence of lack of occupation might be a knowledge deficit of staff concerning what activities actually comprise occupation, and the impact these have on resident wellbeing (Harmer and Orrell, 2008; Innes and Surr, 2001). There is general consensus that occupation should contain 'meaningful activities'. Although attempts have been made to define meaningful occupation (e.g. 'occupation that is personally significant, that gives a sense of belonging and something to do, occupation that addresses psychological and social needs'; Phinney *et al.,* 2007; Harmer and Orrell, 2008), the concept remains inexplicit making it difficult to work with.

A first step in increasing occupation among long term care residents might be simplifying the concept of meaningful occupation into wellbeing enhancing occupation. This can be done by looking at which types of occupation generally lead to greater resident wellbeing. For example, it was found that work related occupation resulted in greater engagement and longer involvement than non-work related occupation, both in people with moderate and severe dementia (Cohen-Mansfield *et al.*, 2010a). The researchers suggested that this finding might be explained by a lifetime exposure to office or household tasks, willingness to assist in a project, or the desire to make oneself useful. Other activities that are assumed to enhance wellbeing in long term care residents with dementia, are reminiscence, listening to music, singing, dancing, and quality interaction about family and social topics (Woods *et al.*, 2005; Harmer and Orrell, 2008). Also creative expression, handcrafts, intellectual occupation, and exercise were found to enhance wellbeing (Innes and Surr, 2001).

Insight into wellbeing enhancing types of occupation will help care practice to focus on what is generally important for residents. Identification also enables studying the impact of the care environment on resident occupation. For example, factors that were found to positively influence resident's occupation are the delivery of small, person centered activities instead of a central activity program (Vollicer *et al.*, 2006; Train *et al.,* 2005), a smaller number of residents in a care unit (Cohen-Mansfield *et al.*, 2010b), a homelike atmosphere of the common living room (Phinney, Chaudhury and O'Connor, 2007; Smit *et al*., 2012), and visual and occupational stimuli (Elliot, 2011).

This study explores resident's involvement in different types of occupation and its relation to wellbeing, and those characteristics of care facilities that might facilitate occupation among residents. The following research questions are studied: (1) In what types of occupation are residents of long term dementia care facilities involved in shared living rooms, and to what extent? (2) Does involvement in certain types of occupation specifically enhance wellbeing of residents? (3) To what extent do the observed care facilities vary in the average time their observed residents are involved in wellbeing enhancing occupation? (4) To what extent is resident's involvement in wellbeing enhancing occupation related to organizational and environmental characteristics of the care facility?

Methods

Study design and sample

Data were derived from a sub-study of the Living Arrangements for people with Dementia (LAD-) study. This is an ongoing study to monitor development and variety in Dutch nursing home care for people with dementia, and consequences of different care environments in terms of group living home care characteristics, staffing models and person-centeredness for residents' quality of life, quality of care, staff ratio and staff wellbeing. Data collection takes place every two years. The design of the LAD-study has been described in detail elsewhere (Willemse *et al*., 2011).

In the first measurement cycle of the LAD-study (2008-2009) 136 long term care facilities for people with dementia participated. These facilities represented traditional large scale nursing homes (n=27), nursing home units in homes for the aged (n=17), and three types of group living home care facilities: 1. group living home care facilities that had 36 or more residents with dementia ('large scale group living homes'; n=31). 2. Small-scale group living homes (defined as less than 36 residents with dementia) that solely provided group living home care (n=26) 3. Small-scale group living homes that also provided other types of long term care at the same location (n=35). The 136 care facilities were all state-financed and had a similar resident population concerning age, gender, cognitive performance, and physical functioning. However, they varied to a great extent in terms of care organization and the primary study outcomes of resident quality of life, quality of care and staff wellbeing. To gain more in-depth insight into facilitators and barriers of high quality dementia care, a sub-study was conducted amongst facilities rated with the best and worst performing on measures used in the original LAD-study (Willemse *et al*., 2011). Using a selection of the quantitative data of the LAD-study, all 136 locations were ranked according to their scores on 1. resident wellbeing

Table 3.1: Description of participating facilities (n=10)

No	Care type	Best/ worst practice & success score	Description
1	Traditional large scale nursing homes	Worst practice -8.67	Nursing home with 119 residents with dementia divided over 4 units, with separate living rooms for approximately 11 residents per living room. In other departments of the facility also live residents with other care needs. The nursing home is located in a rural area, with a large terrace and garden.
2	Traditional large scale nursing homes	Best Practice 2.0	Nursing home with 10 floors with 6 units for people with dementia (144 residents in total) and 6 units for people with somatic problems (144 in total). On each unit live 24 residents, sitting in 2 living rooms during the day (12 residents each).
3	Nursing home unit in a home for the aged	Best Practice 4.67	Dementia care unit in home for the aged with 23 residents, divided over two living rooms of 11 / 12 residents each, located in a small city, with balcony.
4	Care home with 36 or more residents, where group living home care is provided	Best Practice 10.0	Care facility with 90 residents in total, with 15 apartments for 6 residents with dementia each, divided among 2 floors, nearby a large living facility for older people in a city, with garden and balcony.
5	Care home with 36 or more residents, where group living home care is provided	Worst Practice -3,67	Care facility with two units on the ground and first floor of a combined nursing home / home for the aged, residing 24 people with dementia per unit, divided in 2 living rooms for 12 residents.
6	Care home with less than 36 residents, where group living home care is provided next to other types of care	Worst Practice -8.67	Care facility for 24 people with dementia, with three apartments of 8 residents each. The arrangement is attached to a home for the aged, and is located in a rural area.
7	Care home with less than 36 residents, where group living home care is provided next to other types of care	Best Practice 9.33	A care farm with 18 residents with dementia living in three houses (six residents each) and 12 residents with mental disorders, living in three houses (4 people each). The care facility is surrounded by a large amount of farm land and located in a rural area.
8	Care home with less than 36 residents, where solely group living home care for people with dementia is provided	Worst Practice -1.67	Care facility containing four apartments situated on 4 floors with 6 residents each (24 residents with dementia in total), in a big city, with garden on the ground floor.
9	Care home with less than 36 residents, where group living home care is provided next to other types of care	Best Practice 11.67	A care facility with one apartment for six residents with dementia, and one for six residents with somatic complaints on the ground floor with garden in a middle sized city
10	Care home with less than 36 residents, where solely group living home care for people with dementia is provided	Best Practice 8.67	Care facility with 20 residents with dementia, living in 3 apartments of 7 and 6 residents.

measured using quality of life (the Qualidem; Ettema *et al.,* 2007) and pain (MDS-RAI; InterRai, 2005), 2. staff wellbeing measured using job satisfaction, intention to leave (the Leiden quality of work scale; Van der Doef and Maas, 1999) and burnout complaints (Maslach Burnout inventory; Maslach and Jackson, 1986), 3. quality of care measured using person centered attitude of staff (Approach to Dementia Questionnaire; Lintern, Woods and Phair, 2000), and clinical records of the use of physical restraints and psychotropic drugs 4. staff to resident ratio. The scores on these four outcomes were transformed to percentiles and added resulting in a 'total score of success'. It was aimed to select a high and a low scoring facility of each type of long term dementia care facility. The selected care facilities were invited to participate in the sub-study. If they refused, the care facility within the specific type of care with the second highest or lowest score was approached. There was no "worst performing" facility in the category 'homes for the aged' willing to participate in the study. This category was filled with the inclusion of a second best practice in the small scale care facility that solely provided group living home care, since group living home care was of primary interest of the sub-study. This procedure led to the participation of 10 care facilities that are described in Table 3.1.

In one shared living room in every care facility, 5 to 6 residents were selected for observation to collect data on behavior, occupation and wellbeing (n=57). Only residents that were living in the care facility for more than one month were observed. When the observed living rooms consisted of more than six residents that resided there for over one month, the observant consulted the team manager to gather a sample of residents that represented both males and females, people with moderate and severe dementia, and expressed different levels of disruptive behavior to obtain a representative sample of an average nursing home population. Prior to observation, informed consent was given by the primary family caregivers of the observed residents.

Measures

Occupation and wellbeing of residents

As observation tool, the 8th edition of Dementia Care Mapping (DCM) was used (Bradford Dementia Group, 2005; Brooker and Surr, 2006). DCM is a system for structurally examining components of behavior and quality of life of residents of dementia care settings. While it was originally developed as a tool to evaluate and improve quality of care in long term dementia care, it has gained popularity as a research tool. Usually, DCM involves six continuous hours of observation, during which a trained observant (mapper) follows 5 to 8 people over 5-minute intervals. (Sloane *et al.*, 2007; Brooker, 2005). For the current study, DCM was performed during two periods of three hours in each facility for the purpose of including meal-times in the observations. The organization of mealtimes was theorized to be a determining factor for good dementia care since in some care facilities meals were prepared in the kitchen of the shared living room, creating the opportunity for activities and social interaction. During each 5 minute interval at which the residents were observed, the dominant occupation of the residents was coded in one of 23 Behavior Category Codes (BCC), which are presented in Table 3.2. At the same time that BCC's were given to occupation of residents, their wellbeing was observed by ranking ill- or wellbeing values that are rated on a six-point scale. A value of -5, -3

Table 3.2: Overview of time involved in types of occupation, and mean wellbeing during occupation (n=57)

Behavior Category Codes	Mean % of time-frames involved occupation (SD)	Mean wellbeing during occupa-tion (SD)
Articulation – interaction with others	17.62 (14.9)	1.29 (0.52)
Borderline – being passively involved	18.39 (12.40)	.99 (0.92)
Cool – being withdrawn	1.30 (3.42)	-.83 (0.58)
Doing for self – doing self care	3.35 (5.15)	0.99 (0.17)
Expressive – expressive activities	0.86 (2.31)	1.89 (0.91)
Food – involved in eating and drinking	20.48 (8.62)	1.38 (0.58)
Going back – reminiscence	0.47 (1.12)	2.18 (0.77)
Intellectual – involved in intellectual activities like games	0.05 (0.41)	3.00 (-)
Joints – involved in physical activity	0	-
Kum and go – walking around, move	2.62 (5.54)	1.04 (0.71)
Leisure – involved in leisure activities	8.42 (14.37)	1.80 (0.72)
Nod – sleeping, dozing	13.05 (18.62)	0.72 (0.62)
Objects – having attention to lifeless objects	1.14 (2.44)	0.78 (0.61)
Physical - receiving physical care	1.87 (2.20)	1.13 (0.55)
Religion – involved in religious activities	0.17 (0.49)	1.33 (0.82)
Sexual expression	0	-
Timalation – direct involvement of senses, feelings	1.30 (4.71)	1.00 (0.43)
Unresponded to – trying to communicate but getting no response	0.76 (3.86)	-.67 (1.51)
Vocational – task related activities	2.32 (5.34)	1.66 (0.87)
Withstanding – repeated self-stimulation	2.65 (10.20)	0.30 (0.83)
X-cretion – involved in activity around excretion	1.03 (2.20)	1.28 (0.44)
Yourself – talking to oneself	2.20 (8.04)	0.78 (0.38)
Zero option – none of the above stated categories	-	-

and -1 represents levels of ill-being, 1 is the neutral value, and +3 and +5 represent wellbeing.

Organizational and environmental characteristics of care facilities

To study the influence of characteristics of the care organization and individual space of residents, data of the larger LAD-study dataset were used (Willemse *et al.,* 2011). Data on staff to resident ratio were derived from the working schedules of the care facilities. Data concerning the presence of a central activity program and the number of residents were derived from structured interviews with care managers. The size of the common living rooms was measured by research assistants.

To study the possible relationship between wellbeing enhancing occupation and environmental characteristics of long-term care facilities, items of the Physical Environment Evaluation Component of Dementia Care Mapping were measured (PEEC-DCM; Chaudhury, Cooke and Frazee, *in press*). This tool is currently under development to form an environmental supplement to Dementia Care Mapping. For the current paper, the domains 'Continuity of the self', 'Social Interaction', and 'Stimulation' of the PEEC-DCM were studied, since these were theoretically assumed to enhance occupation. The domains respectively represent characteristics that help

preserve or support residents' past activities and preferences; characteristics that facilitate and enable meaningful interaction with others (i.e. resident-resident, resident-staff, resident-family); and characteristics that contribute to an appropriate quantity and quality of sensory experience (Chaudhury *et al.*, 2013).
Since the complete tool was still under development at time of the study, the mapper observed the characteristics once only in every care facility, instead of observing the environment in relation to the residents during the 5 minute interval observations. The mappers were instructed to explain their answers to the questions that required interpretation, so that the research team was able to check whether the answers to the questions were uniform. The used items of the PEEC-DCM and the mapper's instructions are presented in box 3.1.

Box 3.1: Environmental characteristics inventoried in each care facility, based on 3 domains of the Physical Environment Evaluation Component of Dementia Care Mapping (Chaudhury, Cooke and Frazee, 2013).

Please explain the answers to the items beneath

Continuity
1. Homelike décor and furniture in terms of colours, carpet, walls, tables, chairs, cabinets, lamps yes, partly, no
2. Presence of outdoor space yes, partly, no
3. Presence of walking path yes, partly, no

Both continuity and social interaction
4. Presence of occupational stimuli like books, papers, magazines, games, stuffed animals *yes, partly, no*
5. Presence of meaningful objects (objects that have potential value to residents) *yes, partly, no*

Social interaction
6. Presence of separate seating's on care unit outside the living room *yes, partly, no*
7. Furniture is arranged in conversational pattern (stimulating social interaction) *yes, partly, no*

Both social interaction and stimulation
8. Visual stimuli: decoration of the wall, photographs, mobiles, fish tank *yes, partly, no*

Stimulation
9. Presence of blinding glare on floors, furniture *yes, partly, no*
10. Enough daylight *yes, neutral, no*
11. Sound: tv, radio, shouting residents, shouting staff, dish washer *pleasant, neutral, noisy*
12. Smell *pleasant, neutral, smelly*

Analysis
For statistical analysis, the DCM data of the observed timeframes and attached behavior code categories and wellbeing were entered into SPSS version 19. To answer the first research question, the mean percentage of timeframes that all residents were involved in the different occupation types were calculated, as well as the standard deviations. The relationship with type of occupation and wellbeing (second research question) was studied by computing the average wellbeing value during involvement in the specific type of occupation. Concerning the third research question, those occupation types on which the average wellbeing value of

residents was 1.5 points or higher were defined as 'occupation types that enhanced wellbeing of residents'. The cut-off point of 1.5 was chosen in accordance with the cut-off points described by Fossey, Lee and Ballard (2002) in their study on the psychometric properties on Dementia Care Mapping, in which they proposed that a mean wellbeing score of 1.5 or higher represents good to excellent wellbeing, whereas a score of 0.9 to 1.4 represents 'fair' wellbeing, and a score below 0.9 represents low wellbeing in DCM. For all participating care facilities, an 'enhancing occupation score' was calculated, representing the average time their observed residents were dominantly involved in one of the occupation types that corresponded with high levels of wellbeing. To answer the last research question, the participating care facilities were ranked according to their enhancing occupation scores, along with an overview of their organizational and environmental characteristics as observed by the mappers. The characteristics of the two highest and lowest scoring facilities were compared, to see if they prominently differed and might play a role in engaging residents in wellbeing enhancing occupation.

Results

Resident characteristics

87.7% of the observed residents were female. The mean wellbeing score of residents was 1.17 (SD 0.48), representing neutral or 'fair' wellbeing.

Involvement in different types of occupation

In Table 3.2, the percentage of observed timeframes that the study sample of 57 residents were involved in the different behavior category codes are presented. All types of occupation, except for physical exercise ('joints'), sexual expression, and behavior that was not represented in DCM codes ('zero option') were observed. Involvement in intellectual occupation was only observed for one timeframe.

Residents were mostly involved in eating and drinking (20.48% of the observed time), followed by being passively involved (18.39%), indicating that they were observing but not actively engaged. Other common behaviors were interaction with other residents, care staff or visitors, and sleeping or dozing. In 8% of the observed time, residents were involved in leisure activities such as reading and looking in magazines, listening to the radio, or watching TV. Other types of occupation were far less present during the observations.

Occupation types and wellbeing

Examining mean wellbeing values experienced during different types of occupation, a fair mean wellbeing level (mean value of 0.9 – 1.4) was observed during interaction with others, doing self-care, eating and drinking, walking around, receiving physical care, religious activities, involvement of senses, and excretion (leaving the living room to go to the restroom). High mean wellbeing values (+ 1.5) were recorded during expressive, reminiscence, intellectual, and vocational occupation.

Enhancing occupation in care facilities

Wellbeing was enhanced during reminiscence, expressive activities, leisure activities, and vocational occupation and were labeled as 'enhancing occupation'. Intellectual activities were excluded since they were only observed once. Table 3.3 presents the minimum, maximum and average percentage of timeframes that residents within the 10 care facilities were involved in any of the enhancing occupation types including standard deviations. Large variation exist in the average enhancing occupation of residents between care facilities.

Table 3.3: involvement of observed residents per care facility in types of occupation that are related to high wellbeing (n=57)

Care facility	% of timeframes involved in wellbeing enhancing occupation			
	min	max	Mean	SD
1 (n=6)	0	45.20	11.93	18.62
2 (n=6)	0	20.70	4.05	8.21
3 (n=5)	0	52.30	13.20	22.09
4 (n=6)	0	37.70	11.54	17.00
5 (n=6)	0	4.20	0.70	1.71
6 (n=6)	0	63.90	22.50	23.89
7 (n=6)	13.0	43.40	28.92	10.44
8 (n=5)	0	29.90	7.18	12.79
9 (n=6)	0	17.20	6.41	6.99
10 (n=6)	0	29.40	14.08	11.23

Organizational and environmental characteristics and enhancing occupation

In Table 3.4, the care facilities are presented in order of the mean percentage of timeframes that their residents were involved in enhancing occupation, and their organizational and environmental characteristics. When looking at the two highest (facilities 6 and 7) and lowest (facilities 5 and 2) scoring facilities, few characteristics seem to be of importance concerning enhancing occupation in long term dementia care. In particular, there seems to be no relationship between wellbeing enhancing occupation and staff to resident ratio, as pointed out by the average staff ratio of the facility rated highest on wellbeing enhancing occupation, and the average rating of facility 3 that had lowest staff ratio.

The absence of a central activity program – in other words, activities were not primarily offered outside the care units and performed by specialized care workers on a fixed week schedule – did seem to be a potential contributor to engagement in enhancing occupation offered in the shared living room, as did two environmental characteristics derived from the Physical Environment Evaluation Component of Dementia Care Mapping: a homelike, non-institutional interior (domain of continuity), and an interior that stimulates interaction (domain of social interaction).

Discussion

This explorative study shows differences between types of occupation in their potential to enhance wellbeing of people with dementia and in the extent to which these types of occupation are offered, and sheds light on some potential contributors to enhancing occupation. In our sample, reminiscence, leisure, expression, and vocational occupation seem to be of greater value for residents' wellbeing than other types of occupation. Unfortunately, these wellbeing enhancing occupation types were rarely offered - less than 5% of the timeframes on average - to the observed residents. There was much variation found between care facilities participating in this study in engaging the observed residents in enhancing occupation. Whereas in one facility residents were engaged in enhancing occupation during 25% of the observed timeframes on average, in another facility this was only during less than 1%

Table 3.4: characteristics that potentially contribute to wellbeing enhancing types of occupation of ranked care facilities

Care facility	Care organization		Individual space		Continuity			Continuity and social interaction		Social interaction		Social inter. / stimulation	stimulation			
	Staff ratio (hours / week /res)	Central activity program	No. of residents / living room	m^2 per resident	Homelike interior	Walking path	Outdoor space	Meaningful objects	Occupational stimuli	Separate seating's	Interior stimulates interaction	Visual stimuli	Sound	smell	daylight	glare
7	18.67	no	6	8.50	yes	no	yes	yes	yes	no	yes	yes	pleasant	pleasant	yes	no
6	20.49	no	8	8.33	yes	no	yes	yes	partly	yes	yes	Yes	neutral	pleasant	yes	no
10	21.60	no	7	10.00	yes	no	yes	no	yes	yes	yes	yes	pleasant	pleasant	yes	no
3	14.91	no	11	9.09	no	no	yes	yes	no	yes	partly	yes	noisy	neutral	yes	no
1	23.17	Yes	11	6.36	yes	yes	yes	yes	no	no	yes	no	noisy	pleasant	yes	no
4	24.28	Yes	6	10.5	Yes	no	yes	no	partly	yes	yes	yes	neutral	pleasant	yes	no
8	18.67	no	6	5.33	yes	no	no	partly	no	no	yes	yes	noisy	pleasant	no	no
9	17.86	no	6	13.7	no	no	yes	yes	no	yes	partly	no	pleasant	pleasant	yes	no
2	21.63	yes	12	5.91	no	no	no	yes	yes	yes	no	yes	noisy	neutral	yes	a little
5	15.90	yes	11	6.15	no	no	yes	yes	no	partly	no	yes	neutral	neutral	yes	no

of the timeframes. Facilities that engaged their residents in enhancing occupation on a frequent basis more often had a homelike atmosphere, supported social interaction through the environment, and did not have a central activity program.

The findings on wellbeing enhancing types of occupation are generally consistent with literature. Especially reminiscence, expressive and vocational activities were described to have positive effects on mood, engagement, and sometimes even on cognition and behavior in previous research (Woods, 2005; Harmer and Orrell, 2008; Innes and Surr, 2001; Cohen-Mansfield *et al.,* 2010a). Leisure activities, which contained activities such as looking at magazines, reading or knitting in this study, are not frequently mentioned in literature as a type of wellbeing enhancing occupation, possibly because they are often not recognized as an activity. Physical exercise, a type of occupation that is described to positively influence wellbeing (Williams and Tappen, 2007) and which was found to lead to highest mean wellbeing scores in other DCM research (Innes and Surr, 2001), was not observed during this study so no conclusions can be drawn considering its impact on wellbeing. This might be explained by the fact that we observed in resident's common living rooms. Involvement in intellectual activities was only observed once, so no conclusions can be drawn for this type of occupation.

Interaction was not found to be a wellbeing enhancing type of occupation. This might be explained by the quality of interaction. Interaction was rated when residents talked to other residents, care workers, or family for the greater part of a timeframe, but could contain neutral, positive or negative interaction. As Harmer and Orrell (2008) reported, interaction might be only beneficial when it is of good quality. This illustrates the importance of the actual content of a type of occupation.

Consistent with the DCM study of Innes and Surr (2001), staff ratio was not found to be clearly related with time spent in wellbeing enhancing occupation in this study, and therefore seems to be no explanation for low occupation of residents in long term dementia care facilities as was assumed in some earlier studies (Harmer and Orrell, 2008; Train *et al.*, 2005). This suggests that occupation of residents depends on how care workers use the available time and how staff are equipped to engage residents in wellbeing enhancing occupation. Findings from Smith, Mathews and Gresham (2010) suggest that staff training in involving residents by using the daily environment significantly increases occupation, also on the long term, without increasing the number of staff.

Our study findings suggest that the presence of a central activity program does not necessarily have to decrease involvement in enhancing types of occupation as long as it is offered on a complementary basis. In one of the observed facilities in this study, the central program clearly was an extra service for residents, in addition to the provision of occupation in the shared living rooms. However, in the other three with a central activity program, only a few residents were involved during the observation period, leaving remaining residents generally unoccupied. These findings are consistent with findings of Vollicer *et al.* (2006), who assumed that the presence of a central activity program decreases the involvement in meaningful occupation. Also for residents that are regularly involved in central activities, the sole provision of a central activity program might not meet the specific needs of long term care residents. Knight and Mellor (2007) pointed out that a central activity program for long term care residents can emphasize their feelings of living in an institution instead of at home, and may facilitate only superficial interaction

with other residents, although residents with dementia were excluded in this study.
Concerning individual space, the number of residents per living room and the size of the living rooms did not seem to make that much of a difference in terms of involvement in wellbeing enhancing occupation. This conflicts with findings that limiting numbers to between 4 and 9 people optimizes engagement in activities (Cohen-Mansfield *et al.*, 2010a). However, there could have been too little variation in the size of resident groups in the current study to find a relationship, and this might also be dependent on the type of residents and the type of occupation they need.
No relationship was found between occupational and visual stimuli and the provision of wellbeing enhancing occupation. This is in accordance with the findings of Wood *et al*. (2005), who found that the mere presence of stimuli does not automatically mean that residents were involved in activities due to their loss of skills to initiate activities. They have to be actively engaged to be occupied. In our study, sound did not clearly seem to affect involvement of residents in enhancing types of occupation as was found in earlier research (Cohen-Mansfield *et al.,* 2010b).
This study has some methodological limitations and strengths. This study is explorative in nature and not meant to represent daily practice of the participating care facilities, let alone nursing homes in general. Only a small sample of residents (n=57) and living arrangements (n=10) were participating in this study. Our observations were done in two shifts of three hours, observing at least two different care workers per facility. Still, the observations could have been biased by the care workers that were present during observations. Also, the presence of the dementia care mapper might have influenced the study data, although it was tried to limit this bias by informing staff that we observed interaction and behavior, but not about the exact research questions on occupation and wellbeing. If study results are biased by this cause however, it is likely that this would have led to an overestimation of occupation of residents since staff would have want to perform better than usual, making our findings of low occupation even more distressing.
The fact that our observations covered the mealtimes of residents might have led to a bias in average time and types of occupation. Probably, residents would have spent more time in other types of occupation in other observation times than they did now since they would probably be less involved in eating and drinking. The time of the day can also influence mood an behavior of people with dementia. On the other hand, the mean time that residents were observed to be engaged in different types of occupation, resemble observations of other studies using DCM (Sloane *et al.*, 2007). A longer observation period would have limited the potential biases mentioned above.
Dementia Care Mapping is sometimes questioned as a research tool since it was primarily developed to evaluate and improve care practice. Although the observation technique is standardized and performed by trained observers, it has certain psychometric limitations, such as low variability and low inter rater reliability in the wellbeing code (Sloane *et al.*, 2007). Despite these limitations, with the DCM tool behavior and wellbeing can be measured simultaneously, enabling the study of the relationship between both in detail.
In this study, environmental characteristics were studied with use of items of the Physical Evaluation Component of Dementia Care Mapping (Chaudhury *et al.*, 2013). While this tool was still in development at time of data collection of this study, it was only used to observe the environment once by the dementia care mapper, instead of structurally inventory the influence of the physical context alongside observations. Thus, although the items used in this study are evidence based, the way data on characteristics were collected leave them open for interpretation, making the data of limited reliability.
Another limitation is the absence of objective data on the observed residents concerning age, stage of dementia, functional status and disruptive behavior. Although all residents had

to have moderate to severe dementia needing 24-hour care and assistance with their Activities of Daily Living, since these are strict criteria for receiving the type of care subject of this study was studied, residents had individual differences in their behavior and dependency that probably influenced our study data. Subjective statements of the mappers suggested that residents with lower cognitive and functional status were occupied less often than residents with higher functioning levels, as is also indicated in several studies on factors that influence occupation of residents (Kuhn, Fulton and Edelman, 2004; Kolanowski *et al.*, 2006, Dobbs *et al.,* 2005, Smit *et al.*, 2012). Standardized data on these characteristics would have provided more insight into this relationship.

Despite the explorative character of this study with accompanying limitations, its results have important implications for care practice. They show that it is possible to engage residents in wellbeing enhancing types of occupation, and to do so within current means of budget and staff. They also show that the environment might have some influence on activity participation. The next step would be to translate these group results back to the individual resident, with its own preferences and needs. Further research is needed to study which mechanisms cause certain types of activities to be of greater value, or of greater meaning, than others so that care workers can apply this knowledge when making care plans for and preferably with residents. The same holds true for the impact of the environment on resident occupation. For example: does a homelike environment create more opportunities to involve residents in wellbeing enhancing occupation, or is 'feeling at home' of vital importance to enjoy activities? Understanding what makes activities meaningful, and eventually how to involve each unique resident in meaningful occupation, is the key factor for its increase. In order to reach this, it is essential to put wellbeing enhancing occupation on the care facility's agenda, to evaluate the contribution of the organizational and physical environment, and to enable care staff to acquire skills to integrate wellbeing enhancing occupation in practice and to adjust these types of occupation to the individual interests, needs and abilities of residents.

Conflict of interest

None.

Description of authors´ roles

Dieneke Smit analyzed the data and drafted the paper. Bernadette Willemse helped in analyzing the data, and helped to draft the paper as did Jacomine de Lange. Anne Margriet Pot helped to draft the paper, checked the analyses, and is principal investigator of the LAD study. All authors contributed to the design of the LAD study. All authors read and approved the final paper for publication.

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Seize the day!

Chapter 4 – Activity involvement and quality of life of people at different stages of dementia in long term care facilities.

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Seize the day!

Abstract

Objectives Involvement in activities is assumed to positively influence quality of life of people with dementia, yet activity provision in long term care remains limited. This study aims to provide more insight into the value of activity involvement for domains of quality of life of long term dementia care residents, taking resident characteristics and cognitive status into account.

Method Data were derived from 144 long term care facilities participating in the second measurement (2010/2011) of the Living Arrangements for Dementia study. Amongst 1144 residents, the relationship between time involved in activities (Activity Pursuit Patterns; RAI-MDS) and quality of life (Qualidem) was studied using multilevel linear regression analyses. Analyses were adjusted for residents' age, gender, neuropsychiatric symptoms, ADL dependency and cognition. To check for effect modification of cognition, interaction terms of activity involvement and cognitive status were added to the analyses.

Results Despite cognitive status, activity involvement was significantly related to better scores on care relationship, positive affect, restless tense behaviour, social relations, and having something to do. A negative relationship existed between activity involvement and positive self-image. The explained variance in quality of life between residents caused by activity involvement was small.

Conclusion Activity involvement seems to be a small yet important contributor to higher wellbeing in long term care resident at all stages of dementia. Adjusting activities to individual preferences and capabilities might enlarge this relationship. Further research is needed to confirm this hypothesis, using measurement instruments less sensitive to recall bias and differentiating between active and passive activity involvement.

Introduction

In long term care for people with dementia, reaching the best possible quality of life is generally perceived as primary goal. After all, medical treatment options for the dementia syndrome are still limited (Netherlands Society of Clinical Geriatrics [NVKG], 2005; National Institute for Health and Clinical Excellence [NICE], 2006).

According to a wide range of wellbeing theories, involvement in activities plays an important role in reaching good quality of life of all people (Gerritsen, Steverink, Ooms, & Ribbe, 2004). Engagement in activities is assumed to generate feelings of fulfillment and meaning in life (Westerhof, Bohlmeijer, van Beljouw, & Pot, 2010). It helps to express oneself, to fulfill personal goals, and to be recognized by others (Steverink, Lindenberg & Ormel, 1998). In theories specifically directed at people with dementia, occupation is assumed to be important to feel useful, maintain self-esteem, for feelings of belonging, sense of aesthetics and maintenance of abilities (Lawton, 1994; Kitwood, 1997; Brod, Stewart, Sands & Walton, 1999). Several study results from in-depth interviews with people with dementia, residing in the community as well as in long term care facilities, confirm these theoretical assumptions (Gerritsen et al., 2007; Phinney, Chaudhury & O'connor, 2007; Clare, Rowlands, Bruce, Surr, & Downs, 2008; Orrell et al., 2008; Cahill & Diaz-Ponce, 2011).

People with moderate to severe dementia are however largely dependent on their environment to be involved in activities since they often lose the ability to initiate

occupation themselves (Cook, Fay, & Rockwood, 2008). Activity engagement of long term care residents is therefore more and more recognized as indicator of quality of care. Sometimes it is even assumed that a lack of activity involvement will cause excess disability, meaning more loss of skills and functional capacities than can be explained by the disease on its own (Wells & Dawson, 2000).

Many care facilities seem to struggle, however, with engaging residents in activities on a daily basis. Long term dementia care is still generally described as a place where residents are unoccupied for the greater part of the day (Kuhn, Kasayka, & Lechner, 2002; Hancock, Woods, Challis, & Orrell, 2006; Orrell et al., 2008). Although organizational limitations such as low staffing levels are often mentioned as the cause of this phenomenon, some studies suggest otherwise (Innes & Surr, 2001; O'Sullivan, 2011; Edvardsson, Petersson, Sjogren, Lindkvist, & Sandman, 2013; Smit, Willemse, de Lange, & Pot, 2014).

Presumably, the stimulation of activity involvement in long term care residents with dementia is more complex than suggested in current literature. Firstly, care staff may not know how to stimulate activities, especially in people with more severe dementia (Mowrey, Parikh, Bharwani, & Bharwani, 2012). Secondly, they may not yet fully recognize the benefits of engaging residents with advanced dementia in activities for their quality of life, despite the positive effects reported in several studies (e.g. Schreiner, Yamamoto, & Shiotani, 2005; Brooker, Wooley, & Lee, 2007; Verkaik et al., 2011; Volicer, Simard, Pupa, Medrek, & Riordan, 2006). Engaging residents in activities might seem of less value for the wellbeing of residents, than basic physical care, a clean environment and comfort (Clare et al., 2008; Edvardsson et al., 2013) – also the things staff are often judged upon by family caregivers, colleagues and care facility. In addition, care staff often emphasize the value of a quiet environment for people with more severe dementia. The question arises whether activity involvement is still relevant for those with severe dementia and for what reason: do they for example still pursuit status (Gerritsen et al., 2004) or attach value to purpose in life (Mak, 2011)?

The contradiction between the importance of occupation according to quality of life theories, residents' preferences and the first results of research on the one hand, and minor activity involvement in daily care practice on the other hand, expresses the need for more systematic research. In research on the actual relationship between engagement in activities and specific domains of quality of life in people with dementia in long term care settings, individual and disease specific characteristics need to be taken into account. Knowing what exactly is the attributed value of activity engagement for different aspects of quality of life – for example a sense of belonging or positive or negative affect – in people with different stages of dementia, may guide care staff in which way to provide activities. In this study, a first attempt is made to fill this knowledge gap. This explorative study focuses on the following research questions *1) What is the relationship between the time residents are engaged in activities, and separate domains of their quality of life? 2) Does this relationship differ for people with moderate, severe, and very severe cognitive problems (in other words, does cognitive status modify this relationship)?*

Methods

Design and sample

Data were derived from the Living Arrangements for people with Dementia (LAD-) study. The LAD- study is an ongoing study on developments in Dutch nursing home care for people with dementia and consequences of environmental and organizational characteristics - such as group living home care, person centeredness and staffing models - for residents' and staff's wellbeing. Data collection takes place every two years. The design of the baseline measurement of this

study has been described in detail elsewhere (Willemse, Smit, de Lange, & Pot, 2011).

For the present study, data of 144 long term care facilities providing nursing home care for people with moderate to very severe dementia gathered in the second measurement cycle (January - June 2011) of the LAD-study were used. In this second measurement, more elaborate data on activity involvement were collected for the purpose of studying the relationship between activity involvement and quality of life. In the Netherlands, people with a primary diagnosis of dementia are cared for at dementia-specific care units or in dementia-specific homes. A random sample of living arrangements had been selected for each of the five types of nursing home care in the Netherlands. These were two types of traditional nursing home care: traditional large scale nursing homes (n=29) and nursing home units in homes for the aged (n=27). The other types were types of group living home care facilities: group living home care facilities with 36 or more residents with dementia ('large scale group living homes'; n=29), small-scale group living homes (defined as less than 36 residents with dementia) that solely provided group living home care (n=29), and small-scale group living homes that also provided other types of long term care at the same location (n=30). The 144 care facilities were all state-financed.

All residents living in the participating care facilities were eligible to participate in this study. In each care facility, 12 residents were randomly selected by the research group. If there were less than 12 residents with dementia in the facility, all residents were selected. A registered nurse (RN) or certified nursing assistant (CNA) who was mostly involved with a selected resident was asked to fill out observational questionnaires on resident characteristics, activity involvement and quality of life. Since due to feasibility reasons staff could not be trained in filling in these questionnaires, these were provided with detailed instructions on how to answer the questions of the instruments used. They were also invited to contact the research group for assistance at any time. A total of 1389 observational questionnaires were filled out by care staff, a response rate of 89%. Complete data on activity involvement, quality of life and cognitive status were available for 1144 residents with dementia (83% of the returned questionnaires), and were used in the current study.

Measures

Dependent variable: Quality of life

Quality of life was measured with the Qualidem (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007). In contrast to most other quality of life measures for people with dementia, this scale is suited to measure quality of life in people at all stages of dementia (Schölzel-Dorenbos et al., 2007).

For people with mild to severe dementia, the Qualidem is a 37-item observational scale, consisting of nine subscales which are 1. care relationship (7 items, Cronbach's α =.81 in this sample), 2. positive affect (6 items, Cronbach's α =.89), 3. negative affect (3 items, Cronbach's α =.74), 4. restless tense behavior (3 items, Cronbach's α =.74), 5. positive self-image (3 items, Cronbach's α =.64), 6. social relations (6 items, Cronbach's α =.74), 7. social isolation (3 items, Cronbach's α =.51), 8. feeling at home (4 items, Cronbach's α =.65), and 9. having something to do (2 items, Cronbach's α =.60). All subscales were included in analyses, because those with low reliability, consisted of a few items at which low correlation is to be expected that may result

in a low Cronbachs alpha ($\alpha < .65$).

For people at the most severe state of dementia however, certain items of the Qualidem must be excluded from analyses since they cannot be reliably measured in this specific population (Ettema et al., 2007). These items rely on verbal and physical capacities that are absent in people with very severe dementia (for example the items 'asks for more help', and 'wants to leave the care unit'). Conform the official scoring instructions for people with very severe dementia (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2005), the subscales 'positive self-image', 'feeling at home', and 'having something to do' were completely left out analyses for this population. For the six remaining subscales, scores were derived from 18 of the in total 28 items.

In our mixed population of people at all stages of dementia, combined subscale scores were calculated. For each subscale, the scores on the items that could be used for that person were added and divided by the number of items that were used. For example, for the subscale *social relations*, 6 items could be used in people wild mild to severe dementia, with a maximum score of 18 (range of 0 to 3 per item). For people with very severe dementia, only 4 items could be used, with a maximum score of 12. Dividing the subscale scores by the number of items (resp. 6 and 4) generates a maximum score of 3 in both situations.

All Qualidem subscales range from 0 to 3, with a higher score indicating a higher occurrence of the outcome. For example, a higher score on positive affect means more positive expressions of the resident, whereas a higher score on negative affect means more negative expressions.

Table 4.1: The 20 activities listed by the Activity Pursuit Patterns of the MDS-RAI and estimated time of involvement in minutes of study population (n=1144) during three days.

Activities MDS		**Range time involved**	**Mean**	**SD**
1	Playing cards, games, puzzles	0-420	18.36	45.35
2	Using the computer	0-90	0.13	3.20
3	Talking or making a phone call	0-600	45.86	67.38
4	Handwork or art	0-360	7.05	29.27
5	Dancing	0-120	1.53	9.30
6	Exercise or sports	0-180	10.10	21.36
7	Gardening, taking care of plants	0-120	1.04	7.36
8	Helping others	0-90	2.06	8.87
9	Music or singing	0-540	31.02	53.72
10	Pets	0-360	4.42	20.70
11	Reading, writing, cross-word puzzles	0-630	18.38	54.42
12	Spiritual or religious activities	0-360	14.85	36.53
13	Excursion or shopping	0-720	16.39	53.50
14	Take a walk outside	0-540	25.62	50.90
15	Watching TV or listening to the radio	0-2100	143.25	209.54
16	Domestic tasks	0-370	6.89	24.58
17	Cooking	0-300	5.35	19.07
18	Conversation groups	0-360	6.46	22.28
19	'Snoezelen' or sensory stimulation	0-420	5.32	22.95
20	Beauty activities (manicure, hairdressing, make-up)	0-240	9.84	19.54

Independent variable: Involvement in activities

Resident's involvement in activities was measured using the Activity Pursuit Patterns from the Resident Assessment Instrument Minimum Data Set (RAI-MDS; interRAI, 2005). This instrument consists of a list of 20 activities (Table 4.1) for which an RN or CNA answers the question whether or not the resident has been involved in these activities during the three days prior to the date of filling in the questionnaire. For the purpose of this study, we expanded the original Activity Pursuit Patterns questionnaire by adding questions on how many times the person was involved in this activity during these three days, and for how many minutes on average for each time a person was involved.

In Table 4.1, data on the estimated time that residents were involved in the different types of activities are presented. It was found that RNs and CNAs sometimes reported that residents were involved in talking, singing, or watching television or listening to music (activity number 3, 9 and 15) for very large amounts of time, sometimes the whole time that a person was awake. Since the purpose of this study was to study the effect of active involvement in activities on quality of life subscales and not being in a place with background music, TV or chatting, rather than having a conversation on a specific topic, watching the news together or listening to a favorite CD, these three activities were excluded from the analyses. Therefore, the total amount of time of activity involvement was calculated by adding the time residents were involved in the 17 remaining activities during the past three days.

Control variables: Resident characteristics

For each resident, age and gender were assessed. To adjust for possible differences in functioning level, data on ADL dependency were obtained using the KATZ inventory (Katz, 1983), ranging from 1 to 7, with a higher score indicating more dependency in the activities of daily living. The KATZ has good psychometric properties (Cronbach's α = .918 in this sample). Neuropsychiatric symptoms were measured using the NPI-Q (Kaufer et al., 2000; De Jonghe, Kat, Kalisvaart, & Boelaarts, 2003; Cronbach's α = .731), with a range of 0 to 36 and a higher score indicating more neuropsychiatric symptoms. Data on cognitive status were studied with the Cognitive Performance Scale (CPS; Morris et al., 1994; Cronbach's α= .814). The score derived from the CPS ranges from 0 to 6. A score of 0 to 1 accounts for intact or borderline intact cognition. The scores 2 and 3 represent mild and moderate impairment. A score of 4 stands for moderate to severe impairment. A score of 5 implies severe impairment, a score of 6 indicates very severe impairment.

Analysis

Independent T-tests were used to analyse whether the 1144 residents who were included in this study, significantly differed in resident characteristics from those who had to be excluded due to incomplete data on activity involvement or cognitive status (n=245). Characteristics of the residents in the separate groups of cognitive status were compared using ANOVA.

To analyse the relationship between the time residents were involved in activities during the past three days and the domains of quality of life (research question 1), multilevel linear regression analyses (Twisk, 2006) were performed in MLwiN 2.21. Time involved in activities was highly skewed to the left and therefore the variable was categorized into three groups (low involvement: less than 1 hour;

Table 4.2: Characteristics and activity involvement of total study sample and resident groups with mild to moderate, moderate to severe and severe dementia.

	Total study sample n = 1144		**Mild to moderate dementia[1] n = 391**		**Moderate to severe dementia[2] n = 265**		**Severe dementia n = 488[3]**	
	M	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Resident characteristics								
Age (42-101)	84.22	7.57	84.38	7.52	84.35	7.09	83.96	7.93
% female	75.2	-	76.9	-	66.5*	-	78.6	-
CPS (0-6)	3.99	1.50	2.27*	0.97	4*	-	5.36*	0.48
NPIQ (0-36)	11.43	6.63	9.98*	6.08	13.27*	6.22	11.35*	6.94
KATZ (1-7)	5.35	1.65	4.15*	1.70	5.34*	1.40	6.30*	1.05
Activity involvement of residents								
Minutes involved in activities during the past three days (0-1125)	153.77	168.37	221.46	207.30	150.41	151.88	101.36	114.81
% < 1 hour involved in activities during past three days	38.8	-	26.6	-	32.4	-	52.0	-
% 1 – 3 hours involved in activities during past three days	30.2	-	25.1	-	37.4	-	30.1	-
% < 3 hour involved in activities during past three days	31.0	-	48.3	-	30.2	-	17.8	-
Quality of life – qualidem subscales								
Care relationship (0-3)	2.08	0.68	2.10	0.66	1.97	0.64	2.12	0.70
Positive affect (0-3)	2.12	0.68	2.32	0.61	2.17	0.60	1.93	0.73
Negative affect (0-3)	1.07	0.80	0.94	0.74	1.21	0.82	1.10	0.82
Restless tense behavior (0-3)	1.39	0.90	0.99	0.80	1.60	0.81	1.59	0.92
Positive self-image (0-3)#	2.30	0.71	2.26	0.68	2.32	0.73	2.41#	.72#
Social relations (0-3)	1.69	0.64	2.03	0.82	1.71	0.59	1.40	0.57
Social isolation (0-3)	.97	.74	0.82	0.68	1.13	0.70	1.01	0.79
Feeling at home (0-3)#	2.32	0.67	2.22	0.68	2.23	0.67	2.51#	.60#
Having something to do (0-3)#	0.99	0.93	1.34	0.94	0.94	0.87	.58#	.77#

CPS, cognitive performance scale; NPI-Q, 12 item Neuropsychiatric Inventory questionnaire; KATZ, ADL dependency
[1]CPS score 0 to 3 [2]CPS score 4 [3]CPS score 5 or 6
* significant difference compared with other two resident groups, p<.05
# only calculated for residents with CPS score below 6

medium involvement: between 1 and 3 hours; and high involvement: more than 3 hours). Three analyses were performed: 1) unadjusted analyses were performed with the activity involvement categories as independent variables, and the quality of life subscales as dependent variables. 2) the same analyses adjusted for age, gender, ADL dependency and neuropsychiatric symptoms. 3) Additional adjustment for cognitive status based on the CPS using a categorical variable representing mild to moderate (CPS score 0-3), moderate to severe (CPS 4), and severe to very severe dementia (CPS 5 and 6). To analyse whether the results were modified for people with mild to moderate, moderate to severe, and (very) severe dementia (research question 2), additional analyses were performed including the interactions between the activity involvement categories and the cognitive status categories.

Results

Resident characteristics

The resident characteristics are presented in Table 4.2. The total study sample (n=1144) had a mean age of 84.2 (SD7.6) and consisted for 75% of females, which was similar to the residents who were excluded from analyses due to incomplete data (n=245, mean age 82.0, SD7.5; 79% female). Also the score on neuropsychiatric symptoms (NPIQ) did not differ between these groups. Yet, the residents who were included in the analyses had a significantly higher mean score on the KATZ ADL inventory (5.4, SD1.7 compared to 4.9, SD1.8; p<.000), and the Cognitive Performance Scale (3.99, SD1.5 compared to 3.38, SD1.7; p<.000), indicating that on average, they were more impaired than residents who were excluded from analyses.

When comparing the included residents in three groups of different cognitive status based on resident's scores on the CPS, no significant differences existed concerning age of residents. However, a significant higher percentage of male subjects were present in the group of residents with moderate to severe dementia as compared to the higher and lower cognitive status groups. Whereas ADL dependency appeared higher as severity of dementia increased, neuropsychiatric problems were most present in the middle cognitive status group.

Mean involvement in activities

Table 4.1 shows that besides the excluded activities of talking, music and watching television, residents were most time involved in taking a walk outside, reading, games, religious activities, and shopping. The large standard deviations point at large inter-individual variety. Table 4.2 shows that on average, residents were involved in the listed activities for 154 minutes (≈2.5 hours) in total during the past three days (SD=168, range 0-1125). Again, there was much inter-individual variety. Cognitive status seemed to play a role in this: in the group with mild to moderate dementia, 73% of the residents were involved for more than one hour during the past three days. In the groups of residents with lower cognitive status, this percentage dropped (68% for the moderate to severe dementia group; 48% for the severe dementia group).

Table 4.3: Relationship between the time residents with dementia are involved in activities and their scores on different domains of quality of life

	Care relationship			**Positive affect**		
	B (95% CI)	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*	*B (95% CI)*	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*
Medium vs low activity involvement	.089 (.007 - .185)	.050 (-.032 -.123)	.049 (-.033 - .131)	.274*** (.182 - .366)	.226*** (.134 - .318)	.201*** (.109 - .293)
High vs low activity involvement	.172 *** (.078 - .266)	.156*** (.072 - .240)	.162*** (.076 - .248)	.482*** (.390 - .574)	.423*** (.372 - .519)	.378*** (.280 - .476)
R^2	1.3	1.7	2.0	7.8	5.8	4.3
	Negative affect			**Restless tense behavior**		
	B (95% CI)	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*	*B (95% CI)*	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*
Medium vs low activity involvement	.002 (-.110 - .114)	-.033 (-.073 - .139)	-.035 (-.071 - .141)	-.173** (.046 - .300)	-.146*** (.032 - .260)	-.133*** (.021 - .245)
High vs low activity involvement	-.051 (-.063 - .165)	-.013 (-.097 - .123)	-.003 (-.109 - .115)	-.299*** (.172 -.426)	-.205*** (.087 - .323)	-.122*** (.004 - .240)
R^2	0.2	0.2	0	1.9	0.9	0.6
	Positive self-image			**Social relations**		
	B (95% CI)	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*	*B (95% CI)*	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*
Medium vs low activity involvement	-.100 (-1.017- 1.217)	-.080 (-.038 - .198)	-.068 (-.050 - .186)	.229*** (.145 - .313)	.171*** (.087 - .255)	.139*** (.057 - .221)
High vs low activity involvement	-.117* (.009 - .225)	-.159** (.041 - .227)	-.125* (.007 - .243)	.562*** (.478 - .646)	.401*** (.313 - .489)	.326*** (.238 - .414)
R^2	0	0.2	0	13.5	7.4	4.9
	Social isolation			**Feeling at home**		
	B (95% CI)	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*	*B (95% CI)*	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*
Medium vs low activity involvement	-.098 (-.006 -.202)	-.064 (-.028 -.156)	-.064 (-.061 - .189)	-.036 (-.068 - .140)	-.050 (-.052 - .152)	-.032 (-.067 - .134)
High vs low activity involvement	-.190*** (.084 - .296)	-.121* (.025 - .217)	-.107* (.009 - .205)	-.116* (.014 - .218)	-.095 (.007 - .197)	-.057 (.045 - .159)
R^2	1.5	0.8	0.6	0.7	0.6	0.6
	Having something to do					
	B (95% CI)	*B adj [1] (95% CI)*	*B adj[2] (95% CI)*			
Medium vs low activity involvement	.428*** (.295 - .561)	.393*** (.266 - .520)	.381*** (.254 - .508)			
High vs low activity involvement	.859*** (.728 - .990)	.675*** (.548 – .802)	.641*** (.512 - .770)			
R^2	13.9	10.1	9.1			

Quality of life was measured with the Qualidem

[1] Adjusted for age, gender, ADL dependency (KATZ), neuropsychiatric problems (NPIQ)

[2] Adjusted for age, gender, ADL dependency (KATZ), neuropsychiatric problems (NPIQ), and cognitive status (CPS)

* p>0.05 *** p<0.01 *** p<0.001

Time involved in activities and quality of life

Both unadjusted and adjusted multilevel linear regression analyses showed a significant relationship between involvement in activities and several domains of quality of life (Table 4.3). Both medium involvement in activities (1-3 hours of involvement during the past three days) and high involvement (more than 3 hours during the past three days) were related to better scores on positive affect, restless tense behavior, social relations, and having something to do (please note that this subscale consists of the items 'has things to do without help from others', and 'likes to help with chores on the care unit'. It therefore says something about if someone is able to fulfill the need for occupation by themselves, and differs from the outcome of minutes involved in activities). Only high activity involvement was significantly related to less social isolation. High activity involvement appeared to be related to higher scores on the subscale care relationship, but lower scores on positive self-image as compared with low activity involvement. No relationship was found for activity involvement and the subscales negative affect, and feeling at home.

On the subscales positive affect, social relations and having something to do, activity involvement explained a noteworthy proportion of the variance between individuals (resp. 4.3, 4.9 and 9.1% explained variance for the adjusted models). On the other significant Qualidem subscales, explained variance was minimal (care relationship 2%, restless tense behavior and social isolation .6%, positive self-image .0%). Differences in Qualidem subscale scores appeared to be primarily explained by resident and disease related characteristics.

Activity involvement and quality of life for different stages of dementia

Additional analyses to control for effect modification of cognitive status revealed that most relationships between activity involvement and quality that were found of life in the previous analysis applied to the whole study population.

Cognitive status did modify the relationship between the amount of activity involvement and the outcomes on six Qualidem subscales. In Table 4.4, the final adjusted relationships are presented for medium and high activity involvement compared to low involvement and the outcomes on these six subscales for different cognitive status groups. For the mild to moderate dementia group, the relationship with high activity involvement and care relationship was greater than in other groups. Also in the mild to moderate dementia group, the relationship of *medium* activity involvement as compared to low activity involvement with the quality of life subscales positive affect and social relations seemed to be somewhat greater than in other groups, whereas the relationship with *higher* involvement and positive affect and social relations was somewhat smaller than in other cognitive status groups. For people with severe dementia, the association with high activity involvement and restless tense behavior was greater than in other cognitive status groups. The lower cognitive status, the greater the relationship was between high activity involvement and positive affect. The contrary was true for lower cognitive status and having something to do. Finally, a reversed relationship was found for high activity involvement and social isolation for the moderate-sever dementia group. There seemed to be more, instead of less, isolation when this group of residents were highly involved.

Table 4.4: Relationships between time involved in activities and residents' scores on different domains of quality of life for which effect modification of cognitive status was present

	Care relationship	**Positive affect**	**Restless tense behavior**	**Social relations**	**Social isolation**	**Having something to do**
	B adj[2]	*B adj*[2]	*B adj*[2]	*B adj*[2]	*B adj*[2]	*B adj*[2]
Mild to moderate dementia						
medium activity involvement	.049	.236**	-.133***	.201**	-.064	.605***
high activity involvement	.210**	.318***	-.122***	.272***	-.107*	.788***
Moderate-severe dementia						
medium activity involvement	.049	-0.045*	-.133***	.139***	-.064	.381***
high activity involvement	.162***	.378***	-.122***	.326***	.105*	.641***
Severe to very severe dementia						
medium activity involvement	.049	.201***	-.133***	.139***	-.064	.207*
high activity involvement	.162***	.593**	-.306*	.326***	-.107*	.445*

Quality of life was measured with the Qualidem

[2] Adjusted for age, gender, ADL dependency (KATZ), neuropsychiatric problems (NPIQ), cognitive status (CPS)

* p>0.05 *** p<0.01 *** p<0.001

Discussion

This study provides insight in the involvement of long term care residents with dementia in activities, and its contribution for quality of life despite cognitive status. Residents in this study were mildly to very severely impaired in their cognition and functioning, were mostly female and had an average age of 84 years, which is comparable to the study samples of long term care residents with dementia in other research (e.g. Verbeek, Zwakhalen, van Rossum, Kempen, & Hamers, 2012).

On average, residents were involved in activities for about 2.5 hours during three days (listening to music, watching television and having a conversation not included). There was much inter-individual variance in activity involvement. In general, about 1/3 of the residents was involved for less than one hour during three days, 1/3 was involved for one to three hours, and 1/3 for more than three hours. These results support earlier findings that many long term care residents seem to spend the largest part of the day unoccupied (Hancock et al., 2006; Orrell et al., 2008). Due to incomplete data, 17% of the resident sample could not be studied however. Since these residents were found to have a somewhat higher functioning level in terms of ADL dependency and cognitive status, the results might be an underestimation of the average activity involvement of long term care residents. ADL dependency and cognitive status are found to be important explanatory factors for activity involvement of long term care residents (Kuhn, Fulton, & Edelman, 2004; Kolanowski, Buettner, Litaker, & Yu, 2006), also confirmed in our study results showing that the more severely impaired residents were, the less they were involved in the listed

activities.

This study shows that, overall, activity involvement seems to be beneficial for people with dementia, in relation to care relationship (accepts help, no conflicts with care staff), positive affect (is happy, mood can be positively influenced), restlessness (has tensed body language), social relations (has friendly contact with other residents) and having something to do (has things to do without help from others). Involvement for more than 3 hours in three days seems to be more beneficial than medium activation (1 to 3 hours in three days). This holds true for people in all stages of dementia, although the results on 'having something to do' should be interpreted with caution, since people at the most severe state of dementia (CPS = 6) were excluded from analyses of this Qualidem subscale for validity reasons, as was the case with subscales 'positive self-image' and 'feeling at home'. Especially people with severe dementia seem to benefit from higher activity involvement with respect to positive affect and restless tense behavior.

On the other hand high activity involvement was related to lower positive self-image as compared with medium and low activity involvement. Perhaps, high activity involvement also confronts residents with their own inabilities. For people with moderate to severe dementia, high activity involvement was related to more social isolation. The group of residents with moderate to severe dementia significantly consisted of more males, and also suffered from more behavioral problems. The activities offered to these residents might not have been completely suitable for this specific group, or increased negative confrontation with other residents. Activity involvement might have diverse effects, providing pleasure but also negative outcomes such as confrontation with the own functioning. Adverse effects of activity provision were described before by Fritsch et al., (2010), who found higher engagement and alertness of people with dementia who were involved in a specific activity program, but also more feelings of anxiety and sadness in this group. These results are in line with earlier research showing that activity provision is a complex task, and should be carefully adjusted to resident's preferences and capabilities (Perrin, May, & Anderson, 2008). It should be individually determined whether the benefits of an activity outweighs possible downsides.

The sole contribution of activity involvement for resident quality of life appeared to be relatively small in this study; it only explained a small amount of the difference in quality of life found between residents. Quality of life is described to be largely influenced by disease-related characteristics (Castro-Monteiro et al., 2014). Next to the presence of these more dominant factors for quality of life such as ADL dependency and cognitive functioning however, this might be explained by the limited overall time of activity involvement (153 minutes in three days on average). A larger effect cannot be expected from such a small aspect of daily life. Yet the fact that activity involvement is related to several domains of quality of life, showing its diverse impact and meaning for wellbeing consisted with wellbeing theories on dementia (Kitwood, 1997; Gerritsen et al., 2004), is promising.

The relationship between the amount of activity involvement and quality of life might be enlarged when they are adjusted to resident's capabilities, needs, behavior, life history and preferences. Earlier research indeed showed that by training care staff how to adjust activities to the needs and wishes of people with dementia, improved wellbeing, functioning level, and pharmacological restrictions were reported (O'Sullivan, 2011). A more person centered attitude of staff, knowing

more about the life history, specific interests, limitations and strengths of the individual residents, might also result in a better suited activity program (Edvardsson et al., 2013). Activity involvement might also be improved by alterations in the physical environment lowering the threshold for active participation of residents in household activities (Fleming, Goodenough, Low, Chenoweth, & Brodaty, 2014) and combining staff with various education backgrounds so that both the physical as the emotional aspects of long term care are emphasized (Abrahamson, Lewis, Perkins, Nazir, & Arling, 2013). Training to enlarge the knowledge on creating personally meaningful activities, how to use the environment and make activity material available, and how to offer these activities to the individual residents within his or her capabilities, might be the key factor in enlarging activity involvement, also of more impaired residents (Edvardsson et al., 2013).

This study has its limitations. Cross-sectional data were used, giving no certainty about the causality of the relationships found. It is therefore possible that higher quality of life resulted in higher activity involvement instead of the other way around. Furthermore, in order to measure time involved in activities in a large study sample, an instrument with unknown reliability and validity was used because there was no instrument with good psychometric properties available. Several remarks have to be made on this account. First, the activities listed in the questionnaire are a selection of activities that can be offered to residents with dementia. Although no comments were made that care staff missed activities, it could be that residents were involved in other activities resulting in an underestimation of activity involvement. Also, the fact that many data were missing in questionnaires, especially in those addressing people with mild dementia who were found to be more involved in activities, raises the question whether staff were able to reliably recall what residents had done during the past three days. The more so, because they might not have worked the last three days, making them dependent on reports or observations of colleagues. It is likely that our retrospective research method has resulted in an estimation of the time residents are usually involved in the listed types of activities as perceived by the care staff instead of accurate daily records.

Moreover, staff sometimes seemed to be unable to discriminate active from passive activity involvement, which might have resulted in an overestimation of activity involvement. For the activities talking, watching television and listening to music or radio, the reported time of involvement was at times so extreme – some people were found to be involved in watching television for more than 24 hours during the past three days – that they had to be excluded from analyses with consequences for the reliability of the data. Perhaps the misinterpretation of passive activity involvement points out an important cause of limited activity involvement of residents. Staff may perceive that by putting on the TV or radio, they involve residents in an activity. They might not be aware of the necessity to actively involve most residents with dementia in a television or music program to make them capable to capture its meaning. Raising awareness on how to differentiate passive from active activity provision might enlarge resident's involvement. In future research, activity involvement would best be captured by an independent observer. When this is not possible, staff should be trained in observing actual activity involvement, including the differentiation between passive and active involvement in order to capture the concept accurately.

Also the Qualidem measure for quality of life seemed to have some limitations in this study sample. For people with severe dementia, many items were left out analyses, while individuals with severe dementia often vary in what they can and cannot still express so that possibly more items could have been included in analysis. Moreover, some subscales suffered from low reliability. Finally, one might argue that depression was not accurately taken along in analyses as a confounding factor. Although depressive symptoms are represented in the NPI-Q, it might have

been more appropriate to solely measure this factor, since its influence on quality of life and its high prevalence in long term dementia care (Verkaik, Francke, Van Meijel, Ribbe & Bensing, 2009).

Despite these limitations, this study provides ground that activity involvement is important for the quality of life of residents with dementia in long term care facilities, and something care facilities should invest in, also when residents are severely impaired. It seems to be important however to look at individual needs, preferences and capacities to maximally impact quality of life and prevent undesirable effects of activity involvement. Further research is needed to study the effect of individually adjusted activities on quality of life, and how to apply these in practice in a feasible manner so that activity provision can be broadly implemented. In future research, other measurement instruments should be considered to accurately capture activity involvement of long term care residents with dementia. Several well-tested observational methods are available, such as Dementia Care Mapping (Fossey, Lee, & Ballard, 2002) and Observational Measurement of Engagement (Cohen-Mansfield, Dakheel-Ali, & Marx, 2009). These are valid instruments that give more in-depth insight into what activities are actually provided and how these are valued by residents, as we have seen in one of our substudies where 57 residents were observed on activity involvement and wellbeing (Smit, Willemse, de Lange , & Pot, 2014). However, these methods are very intensive and therefore less suitable for large scale use. Therefore, the development of a valid research instrument to measure activity involvement in large study samples is desirable, that is less sensitive to the subjective memory of those who report activity involvement, and that differentiates between active and passive activity involvement.

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Seize the day!

Chapter 5 – Daily occupation of care home residents with dementia as observed by staff – implications for care and research practice.

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Submitted

Seize the day!

Abstract

Objectives The importance of meaningful occupation for the wellbeing of care home residents living with dementia is increasingly recognized. Yet, the existing literature mentions low activity levels in this population. With more recognition for the need for meaningful occupation in modern dementia care on the one hand, but higher care needs of residents on the other, it is desirable to monitor their daily occupation and wellbeing. The measurement instruments that are available for this purpose lack feasibility however. With an alternative instrument using staff observations, this study aims to provide insight in the current level of occupation of care home residents with dementia. Furthermore, the relationship between the involvement in types of occupation and the wellbeing of care home residents at different stages of dementia was studied.

Methods A sample of 171 residents representing 50 dementia care homes were observed by regular care staff. After receiving a one-hour training, single staff members observed two randomly selected residents during three eight-hour shifts. Daily occupation and wellbeing were observed during one minute every hour using a standardized method, leading to 4072 one-minute observations on occupation and wellbeing. Standardized measures were used to examine the resident's level of functioning.

Results Residents were mostly involved in sleeping, eating or drinking, conversation and looking around. Overall, having visitors, playing games, physical exercise, and being busy with the past, most strongly related to wellbeing. Residents with severe dementia benefitted most from playing games, being busy with the past, eating and drinking, and looking around.

Conclusion Several occupation types were related to higher wellbeing of people with dementia, but these were not frequently observed. Staff training and family involvement might help to increase wellbeing-enhancing occupation in care homes. Although more research is needed to test its reliability, using staff observations in monitoring occupation seems promising.

Introduction

Occupation and wellbeing of care home residents with dementia

Daily occupation of people with dementia living in care homes refers to engagement in daily life (Kitwood, 1997; Perrin, May, & Anderson, 2008). It can entail involvement in recreational activities, but also to involvement in domestic tasks, eating and drinking, having interest in objects, social conversation, receiving physical care, and so on (Elliot, 2011). Occupation is described to be meaningful for a person with dementia, when it generates feelings like pleasure or enjoyment, or creates a sense of connection and belonging, autonomy or identity (Phinney, Chaudhury, & O'Connor, 2007).

The importance of meaningful occupation for the wellbeing of care home residents with dementia has been addressed frequently over the years (Moyle & O'Dwyer, 2012). People with dementia and their family perceive meaningful occupation as a key aspect of the resident's quality of life (Cadieux, Garcia, & Patrick, 2013). Types of occupation that were found to specifically enhance the resident's wellbeing are reminiscence activities, physical exercise, participating in household chores and listening to individually preferred music (Innes & Surr, 2001; Smit, Willemse, de

Lange, & Pot, 2014). Residents seem to benefit most from types of occupation that are adjusted to the personal preferences and capabilities of residents (Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010). But compared to doing nothing at all, residents were also found to benefit from activities that were not personally adjusted (den Ouden et al., 2015).

Unfortunately, facilitating meaningful occupation in dementia care homes has proven to be difficult. In several studies, a dearth in activity engagement was observed (Hancock, Woods, Challis, & Orrell, 2006; Orrell et al., 2008; Kuhn, Fulton, & Edelman, 2004; Smit, de Lange, Willemse, Twisk, & Pot, 2016). When looking closer at the types of occupation residents with dementia were engaged in, they were found to be mostly involved in occupation types with a low potential for wellbeing such as sleeping, sitting and doing nothing, or other passive occupation types like watching TV, eating and drinking, or being involved in conversation (den Ouden et al., 2015; Innes & Surr, 2001; Kuhn, Kasayka, & Lechner, 2002; Sloane et al., 2007; Smit et al., 2014). Types of occupation with a higher potential to increase wellbeing, like reminiscence, physical exercise, creative activities, doing puzzles or games, or vocational activities, were rarely observed.

A changing care home environment regarding resident's occupation

However, most studies that reported on the level of occupation of activity involvement of residents with dementia date from several years ago. The level of meaningful occupation might have been increased over the years now that this topic has received more attention in dementia care policy in high income countries (UK Government, 2016). On the other hand, in most high income countries, people with dementia enter care homes at a later stage of their condition in comparison to a decade ago, as a consequence of 'aging in place policies'. These policies are meant to enable older people to stay in their own homes for as long as possible, also when they increasingly need care (Prince, Prina, & Guerchet, 2013; Rodriques, Huber, & Lamura, 2012). Since having more cognitive and physical limitations is strongly related to lower activity involvement, even less meaningful occupation might be expected among today's care home residents with dementia (Dobbs et al., 2005; Smit, de Lange, Willemse, & Pot, 2017; Zimmerman et al., 2005). This is an urgent call for change, because as our previous research showed, people with severe dementia can still benefit from various activities in terms of positive mood and decreased agitation (Smit et al., 2016).

Challenges in measuring occupation

In order to meet the need for meaningful occupation of the changing population of care home residents with dementia, it is important to regularly monitor the level of daily occupation and the effect on wellbeing, also with respect to different stages of cognitive impairment.

Today, there are different measurement instruments that can be used for this purpose. These instruments suffer from problems regarding feasibility and accuracy however. Few standardized questionnaires are available that can be used for large scale data collection. The Activity Pursuit Patterns (RAI, MDS; interRAI, 2005) focuses only on recreational activities and not on daily occupation of residents. Furthermore, its retrospective character – staff is asked to recall what activities residents have done during the past three days - might lead to recall bias, especially since care staff often work unregularly, forcing them to rely on the transfer of information of colleagues.

Also the observational instruments have their limitations. The prevailing method is Dementia Care Mapping (DCM; Brooker & Surr, 2005), where 5 to 6 residents are observed simultaneously for several hours by trained observers. Because the method is costly usually small resident samples have been observed, making the evidence harder to generalize to the larger population.

Furthermore, the presence of an observer might influence the behavior of both residents and staff. Other observational methods like the Passivity in Dementia Scale (PDS; Colling, 1999) and the Assessment Tool for Occupation and Social Engagement (ATOSE; Morgan-Brown, Newton, & Ormerod; 2013) face comparable problems. Recently, the Maastricht Electronic Daily Life Observation (MEDLO; De Boer et al., 2016) instrument is developed, that uses a simple digital tool to register activity involvement of residents, making it more easy to study larger groups of residents. Still, the use of trained researchers to observe occupation amongst residents is time consuming and expensive, and might influence common behavior.

Purpose of this study

In the present study, the daily occupation of care home residents with dementia and the relationship with wellbeing, was studied. An alternative research method using observations by the regular care staff of care homes on fixed short time-frames was applied. Different stages of dementia were taken into account. The following questions were studied:

1a) To what extent are residents of dementia care homes involved in different types of occupation?

1b) Is the level of involvement in types of occupation different for residents at different stages of dementia?

2a) What is the relationship between different types of occupation and resident wellbeing?

2b) Is the relationship between the types of occupation and wellbeing different for residents at different stages of dementia?

With studying these questions using this new instrument, we hope to provide more clarity in the daily occupation amongst residents with dementia and the relationship with wellbeing as well as stage of dementia, and propose a feasible alternative to the currently available measurement instruments in order to frequently monitor occupation levels in dementia care.

Methods

Study design & sample

Design

Data were derived from a sub-study of the Living Arrangements for people with Dementia (LAD-) study. The LAD-study is an ongoing study to monitor the development and variety in Dutch nursing home care for people with dementia, and consequences of different care environments in terms of group living home care characteristics, staffing models and person-centeredness for residents' quality of life, quality of care, staff ratio and staff wellbeing. Data collection takes place every two years. The overall design of the LAD-study has been described in detail elsewhere (Willemse, Smit, de Lange, & Pot, 2011).

This sub-study had an observational design, using data on the relation between the daily occupation and wellbeing of 171 care home residents living with dementia, that staff measured during 4072 one-minute observations during while doing their regular work.

Study sample

In the third measurement cycle of the LAD-study (2013-2014) 54 dementia-specific long-term-care homes participated. These care homes represented traditional large scale nursing homes, dementia-specific nursing home units in homes for the aged, small scale group living care homes (max. 36 residents) and larger group living care homes with more than 36 residents in total. The 54 care homes were all state-financed and had a had a similar resident population concerning age, gender, cognitive performance, and physical functioning.

For the current study, the care homes were asked to select two care staff members of education level 3 (resembling Nursing Assistants, Certified Nursing Assistants and Registered Nurses in the U.S.) that could observe the occupation and wellbeing of two residents each (thus four residents per care home), during three eight-hour day- or evening shifts. The residents to be observed were randomly selected by a research assistant. All residents on the participating dementia units were eligible to participate. In 50 of the 54 care homes the observations actually took place. In 16 care homes, the observations were partially performed: less than four residents were observed, or residents were observed for less than three shifts. All available observations were included in our study.

Measurements

Daily occupation and wellbeing of residents

Observation procedure To collect data on daily occupation and wellbeing of residents, the observing staff members were asked to choose three shifts in the forthcoming two weeks, to do the observations. They had to make sure that they were available the entire shift, and did not have to leave for a meeting or conversation. Prior to the observations, staff members received a one-hour training by a research assistant on how to judge involvement in the types of occupation, and score the categories of wellbeing. The staff members received a booklet with observation forms. They had to fill in an observation form for both selected residents on every hour of the shift in which they observed. They were advised to set an alarm on their cellphone as a reminder to fill in the forms every hour. Every hour, they observed the resident for one minute to see what the resident was doing and what his or her level of wellbeing was during that minute.

Occupation types During one minute of observation the occupation of the residents was coded in one or more of 23 occupation types that are listed in Table 5.1. In Table 5.1, a distinction is made in high and low potential occupation types, based on the expected relationship with wellbeing as described in Dementia Care Mapping (DCM) literature (Innes & Surr, 2001; Kuhn et al., 2002). The occupation types were inspired by items of the activity types of the 7th and 8th edition of DCM (Bradford Dementia Group, 1997; 2005) and the activity types of the Activity Pursuit Patterns (InterRai, 2005). Items of these measurement instruments were selected if they were found to be commonly observed in previous research, and substantially differed from the other types of occupation in order to make it easier for our observers to differentiate the types of behavior. Furthermore, the items were strongly simplified and described in easily observable terms, so that care staff could easily recognize the types of occupation and a one hour training was sufficient.

In our instrument, the observers could list the options ‘not present’ and ‘other, namely ….’ . Because ‘having visitors’ was repeatedly mentioned in the ‘other, namely’ category, we included this occupation type in the analyses. ‘Not present’ was left out of analyses, because this option held no information on what the residents were doing and wellbeing could not be observed.

Wellbeing For measuring wellbeing, the observer answered the question ‘What mood is the resident in?’ for every minute of observation. Inspired by elements of the DCM method to capture ill- or wellbeing, the answer categories were 0: very sad or angry, extreme negative

mood; 1: substantial signals of negative mood, sad, irritable; 2: small signals of negative mood, grumpy; 3: neutral, neither positive nor negative mood; 4: satisfied, happy, relaxed, smiling, positive mood; 5: very happy, very cheerful, very positive mood.

Resident characteristics

To take into account the potential influence of differences in demographics and the functioning level of residents, the observing staff were asked to complete a questionnaire about the background characteristics of the selected residents, prior

Table 5.1: Occupation types of staff observations

High potential occupation types*	
1	**Conversation** – talking with other residents, care staff or visitors
2	**Beauty activity** – care staff or resident is brushing hear, putting on make-up, painting nails
3	**Creative activity** – doing a creative activity like drawing, crafts, singing
4	**Eating or drinking** – eating or drinking
5	**Activity related to the past** – talking about the past, looking at old pictures, reading life history book, reminiscence
6	**Busy with the mind** – reading a book, paper or magazine, doing a puzzle
7	**Exercise or sports** – physical activity
8	**Playing games** – having fun, enjoy something, doing a game
9	**Attention for an object** – Being busy with an object like a purse, stuffed animal, napkin
10	**Receiving physical care** – receiving physical care
11	**Spiritual or religious activity** – Busy with a religious activity like singing religious songs, watching or listening to a service, praying
12	**Stimulating the senses** – picking, peeling, feeling with the hands, getting a massage
13	**Domestic tasks** – involved in household chores like doing the dishes, peeling potatoes, helping with cooking
14	**TV or music** – Watching TV or listening to music, only when the resident is truly involved
15	**Having visitors**
Low potential occupation types*	
16	**Looking around with attention** – Looking around with attention, but undertaking nothing
17	**Being withdrawn** – sitting with the eyes closed while being awake
18	**Talking to oneself** – talking to oneself, talking to an imaginary person
19	**Walking around** – walking around, pacing, dancing
20	**Sleeping** – sleeping, dozing, nod
21	**Seeking attention** – calling or talking without anyone responding
Remainder	
22	**Other** – something else, namely: ….
23	**Not present** – not on the unit, or to the restroom

* The classification of high and low potential occupation types is based on Dementia Care Mapping Literature (e.g. Innes & Surr, 2001; Kuhn et al., 2002)

to their observations. First, data on age and gender were collected. Dependency in Activities of Daily Living (ADL) was measured with the Katz inventory (Katz, 1983), ranging from 1 to 7, with a higher score indicating more dependency in the activities of daily living. The Katz has good psychometric properties (Cronbach's α = .932 in this sample). Neuropsychiatric symptoms such as agitation, depression or apathy were measured using the Neuropsychiatric Inventory Questionnaire (NPI-Q; De Jonghe, Kat, Kalisvaart, & Boelaarts, 2003; Kaufer et al., 2000; Cronbach's α = .701), with a range of 0 to 36 and a higher score indicating more neuropsychiatric symptoms. Cognitive status was obtained with the Cognitive Performance Scale (CPS; Morris et al., 1994; Cronbach's α= .765). The score derived from the CPS ranges from 0 to 6. For studying the involvement in types of occupation of people at different stages of dementia, a categorical CPS variable was created representing mild to moderate (group 1; CPS score 0-3), moderate to severe (group 2; CPS 4), and severe to very severe dementia (group 3; CPS 5 and 6), as was done in previous research (Smit et al., 2016).

Statistical methods

For statistical analysis, the data on the types of occupation and level of wellbeing during each minute of observation were entered into STATA 12.1.

To answer research question 1, the mean percentage of the observations that all residents were involved in the different occupation types were calculated. This was done for all residents together, as well as for the three resident groups based on their stage of dementia. Differences in involvement in occupation types across the residents at different stages of dementia were detected by non-overlapping confidence intervals (research question 1b).

For research question 2, the relationship with type of occupation and wellbeing was studied by performing multilevel linear regression analyses. Multilevel analyses were performed to control for the fact our data was clustered (Twisk, 2006). Based on Log likelihood tests, we controlled for the level of the resident as well as the level of observer. The level care home did not improve the statistical model further and was therefore disregarded.

Involvement in an occupation type (yes/no) was labeled as independent variable, and the wellbeing score during the corresponding minute of observation as dependent variable. Resident

Table 5.2: Resident characteristics of total sample and groups divided according to stage of dementia

	Total study sample n = 171		**Mild to moderate dementia[1] n = 83**		**Moderate to severe dementia[2] n = 43**		**Severe to very severe dementia[3] n = 45**	
Resident characteristics	**M**	**SD**	**M**	**SD**	**M**	**SD**	**M**	**SD**
Age (54-100)	84.65	7.77	85.82	6.15	82.19*	8.30	84.82	9.43
% female	72.5	-	71.1	-	67.4	-	80	-
CPS (0-6)	3.50	1.50	2.23	0.95	4***	-	5.36***	0.49
NPIQ (0-30)	10.62	6.13	8.38	4.90	12.29***	7.09	13.20***	5.79
KATZ (1-7)	4.68	1.94	3.46	1.79	5.21***	1.25	6.42***	.92

[1] CPS score 1, 2 or 3; [2] CPS score 4; [3] CPS score 5 or 6

* p<.05 ** p<.01 *** p<.001 significantly different as compared to reference group mild to moderate dementia[1]

characteristics were entered in the statistic model as potential confounding variables.
To answer research question 2b, additional analyses were performed including the interactions between the occupation types and the cognitive status categories.

Results

Resident characteristics

In Table 5.2, the mean characteristics of the complete sample are presented, as well as the characteristics of the mild to moderate, moderate to severe, and severe to very severe dementia groups. Overall, the mean age of the participating residents was 85 years. Almost three quarters of the sample was female. On average, the participants had moderate to severe dementia, and generally had some behavioural symptoms. On average, they were dependent in most ADL tasks based on their high scores on the Katz measure.
The group with mild to moderate dementia had the lowest mean NPI-Q and Katz scores. The group of residents with moderate to severe dementia also had lower scores than the group with severe to very severe dementia. The group of residents with moderate to severe dementia consisted of somewhat younger residents as compared with group of residents with mild to moderate dementia.

RQ 1a: Involvement in different types of occupation

The number and percentage of the different types of occupations that were classified during the observations, are shown in Table 5.3.
When classifying the types of occupation into high and low potential types of occupation as presented in Table 5.1, we see that residents were observed to be engaged in 'high potential occupation types' within about 95% of the observed time frames. In 56% of the observed time frames, low potential types of occupation were observed.
The type of occupation that was observed most was sleeping (observed in 24.4% of the time frames). Almost as frequent, residents were involved in eating and drinking. Residents were involved in conversation with others in around 20% of the observed time frames. In 14% of the observations, residents were found to be actively looking around. Watching TV or listening to the radio, being busy with the mind, stimulating the senses, playing games, and walking around was perceived in 5 to 10% of the observed time frames. The other types of occupation were observed in less than 5% of the observed minutes.
Types of occupation that were not classified and were mentioned under the category 'other' were: whistling, just finished eating, being sick, birthday, hallucinating, helping transferring co-resident, waiting for meal, being upset.

RQ 1b: Involvement in different types of occupation for different stages of dementia

The involvement in types of occupation across the three resident groups with mild to moderate, moderate to severe, and severe to very severe dementia are presented in the last columns of Table 5.3. Residents with more cognitive impairment were less involved in high potential types of occupation, and more involved in low potential types of occupation then residents with a better cognitive status.

Table 5.3: Frequency of involvement in types of occupations in 4072 minutes of observation

	Total sample		Mild - moderate dementia[1]		Moderate-severe dementia[2]		Severe-very severe dementia[3]	
	Number of observed occupation types	% of total minutes of observations (n=4072)	Number of observed occupation types	% of total minutes of observations (n=1976)	Number of observed occupation types	% of total minutes of observations (n=1016)	Number of observed occupation types	% of total minutes of observations (n=1080)
High potential occupation types								
Eating or drinking	986	24.21	493	24.95	236	23.23	257	23.80
Conversation	886	21.76	575	29.10	194	19.09	117	10.83
TV or music	352	8.64	210	10.63	97	9.55	45	4.17
Busy with the mind	250	6.14	189	9.56	38	3.74	23	2.13
Stimulating the senses	226	5.55	54	2.73	59	5.81	113	10.76
Playing games	213	5.23	156	7.89	38	3.74	19	1.76
Beauty activity	175	4.30	107	5.41	29	2.85	39	3.61
Attention for an object	171	4.20	47	2.38	55	5.41	69	6.31
Domestic tasks	167	4.10	131	6.63	28	2.76	8	0.74
Activity related to the past	134	3.29	87	4.40	32	3.15	15	1.39
Creative activity	113	2.78	80	4.05	26	2.56	7	0.65
Receiving physical care	75	1.84	29	1.47	25	2.46	21	1.94
Having visitors	54	1.33	30	1.52	9	0.89	15	1.39
Physical activity	39	0.96	21	1.06	13	1.28	5	0.46
Spiritual or religious activity	31	0.76	25	1.27	6	0.59	0	-
Total high potential types	*3872*	*95.09*	*2234*	*113.05*	*885*	*87.11*	*753*	*69.94*

Low potential occupation types								
Sleeping	995	24.44	419	21.20	197	19.39	379	35.09
Looking around with attention	571	14.02	233	11.79	146	14.37	192	17.78
Walking around	295	7.24	153	7.74	98	9.65	44	4.07
Being withdrawn	235	5.77	103	5.21	33	3.25	99	9.17
Talking to oneself	137	3.36	48	2.43	31	3.05	58	5.37
Seeking attention	48	1.18	7	0.35	16	1.57	25	2.31
Total low potential types	*2281*	*56.01*	*963*	*48.72*	*521*	*51.28*	*797*	*73.79*
Remainder								
Not present	252	6.19	150	7.59	68	6.69	34	3.15
Missing	218	5.34	87	4.40	80	7.87	51	4.72
Other	32	0.79	24	1.21	3	0.30	5	0.46

Because the observers could register more than one type of occupation during each interval, the percentage of occupation types exceed the 100%.
[1]CPS score 0 to 3; [2]CPS score 4; [3]CPS score 5 or 6

Table 5.4: The relationship between occupation types and resident wellbeing of the total sample, and observations of residents with different stages of dementia

	Total sample		Mild - moderate dementia[1]		Moderate-severe dementia[2]		Severe-very severe dementia[3]	
	B#	**SE**	**B*b***	**SE**	**B*b***	**SE**	**B*b***	**SE**
High potential occupation types								
Eating or drinking	.110***	.027	.080	.039	.078	.056	.192***	.052
Conversation	.316***	.031	.351***	.040	.381***	.065	.105~	.075
TV or music	.081*	.043	.081	.056	.026	.081	.190	.114
Busy with the mind	.184***	.050	.186	0.058	.202	.121	.140	.158
Stimulating the senses	.084	.062	.208	.124	-.019	.117	.072	.088
Playing games	.588***	.053	.568***	.062	.635***	.123	.663***	.182
Attention for an object	.035	.065	-.080	.130	-.016	.113	.143	.099
Beauty activity	-.105	.057	-.096	.073	-.332*	.136	.047	.120
Domestic tasks	.264***	.059	.201**	.067	.589***~	.139	.038	.261
Busy with the past	.399***	.069	.365***	.087	.390**	.140	.569**	.186
Creative activity	.241**	.074	.258**	.086	.109	.161	.469	.286
Receiving physical care	-.360***	.088	-.109	.154	-.650***~	.145	-.310	.157
Having visitors	.638***	.111	.693***	.140	.844**	.270	.308	.242
Physical activity	.443***	.119	.400*	.160	.564**	.213	.342	.314
Spiritual or religious activity	.211	.135	.084	.152	.670*~	.289	*Not observed*	
Low potential occupation types								
Sleeping	-.239***	.31	-.395**	.046	-.209**~	.067	-.049~	.053
Looking around with attention	.045	.037	-.007	.057	-.051	.071	.206***~	.068
Walking around	-.086	.047	-.085	.064	-.173*	.083	.098	.123
Being withdrawn	-.384***	.052	-.509***	.078	-.340**	.130	-.260**~	.083
Talking to oneself	-.168**	.070	-.417***	.117	-.363*	.145	.165~	.110
Seeking attention	-.644***	.110	-.880**	.286	-.344	.186	-.783***	.155

[1]CPS score 0 to 3; [2]CPS score 4; [3]CPS score 5 or 6

* p<0.05; ** p<0.01; *** p<0.001

Adjusted for age, gender, ADL dependency (KATZ), neuropsychiatric problems (NPIQ), cognitive status (CPS)

b Adjusted for age, gender, ADL dependency (KATZ), neuropsychiatric problems (NPIQ)

~ Significantly different from reference group (mild to moderate dementia)

The comparison of confidence intervals revealed that residents with more cognitive problems were less involved in conversation, playing games, and domestic tasks, and more involved in stimulation of the senses (group 3 as compared to group 2, and group 2 as compared to group 1). People with severe to very severe dementia (group 3) were more involved in sleeping, and being withdrawn, and less involved in creative activities, watching TV, and walking around as compared to both other resident groups (group 1 and 2). Compared to residents with mild dementia (group 1), they were also found to be more involved in having attention for an object, actively looking around, talking to themselves, and seeking attention. They were less involved in activities related to the past and being busy with the mind as compared to group 1.

RQ 2a: Type of occupation and wellbeing

In the first column of Table 5.4, the relationship between the occupation types and resident wellbeing in all observations is presented, when controlling for resident characteristics as potential confounding factors. The occupation types 'having visitors' and 'playing games' had the strongest relationship with wellbeing, followed by 'physical activity' and 'activity related to the past'. Next, having a conversation with others and doing domestic tasks strongly related to higher wellbeing. Creative activities, being busy with the mind and with eating or drinking also positively influenced wellbeing, but to a less extend. Watching TV or listening to music had a minor positive relationship with wellbeing.

'Seeking attention' was found to have a strong negative association with wellbeing, followed by 'being withdrawn', 'receiving physical care', 'sleeping', and 'talking to oneself'.

The occupation types 'stimulation of the senses', 'attention for an object', 'beauty activities', 'spiritual or religious activities', 'looking around with attention' and 'walking around' were not related to wellbeing.

RQ 2b: Type of occupation and wellbeing for people at different stages of dementia

The relationship between type of occupation and wellbeing was found to vary for people at different stages of dementia. Group 1 (mild to moderate dementia) was found to be the only group that benefitted from being busy with the mind, like reading or doing a puzzle.

Doing domestic tasks and religious activities were found to have the largest positive relationship in group 2 (moderate to severe dementia). In this group, 'walking around' and 'receiving physical care' had a stronger negative relationship with wellbeing, than in the other groups (1 and 3).

For the residents with severe to very severe dementia (group 3), the positive relationship with 'conversation', 'physical activity', 'having visitors' and wellbeing was not present. The occupation types 'looking around with attention' and 'meals' were positively related to wellbeing in this resident group, but not in group 1 and 2. The negative relation of 'being withdrawn', 'sleeping', and 'talking to oneself' with wellbeing, was found to be smaller for people with severe to very severe dementia.

Discussion

This study aimed to provide insight in the current level of occupation of care home residents with dementia. Furthermore, the relationship between the involvement in types of occupation and the wellbeing of care home residents at different stages of dementia was studied. For the purpose of monitoring daily occupation in a more feasible way, we experimented with a new measurement instrument using staff observations.

<u>Current levels of daily occupation of residents of dementia care homes</u>

In our study, the average dementia care home resident was involved in 'sleeping, eating or drinking, talking with staff or other residents, or looking around with attention' for the largest part of the time. This is consistent with the existing literature (Brooker, 2005; Harper-Ice, 2002; den Ouden et al., 2015; Perrin, 1997; Sloane et al., 2007; Smit et al., 2014), confirming low levels of active types of occupation amongst

care home residents with dementia.
However, when looking at the amount of time intervals that residents were involved in high and low potential types of occupation, the occupation levels were higher than previously mentioned (Sloane et al., 2007). In our study, residents were observed to be engaged in 'high potential occupation types' within about 95% of the observed time frames. In 56% of the observed time frames, low potential types of occupation were observed. While in the DCM literature, a range of involvement in high potential behavior of 28-87% and of 8-31% has been described.
An explanation for these differences might be that with DCM, the observers have to choose one type of behavior in every interval, whereas our observers could register more occupation types per time interval. The higher occupation levels in our study might also be the result of our observers being care staff instead of researchers. Since the observing staff were familiar with the study subjects, they might have recognized types of occupation more easily than unfamiliar observers. It is also possible that our observers were not able to choose between types of occupation, and therefore chose several types of occupation at once. However, the proportion in which the types of occupation occurred (for example the involvement in meals as compared with the involvement in conversation) resembled that of previous research, pleading against the latter hypothesis. Nonetheless, it could also be that high potential occupation has increased among dementia care home residents in the Netherlands, resulting from the improved recognition of occupation as an important aspect of life in this resident group. But given the fact that low potential occupation was also high in our study, this conclusion seems premature.

Types of occupation and wellbeing
Various types of occupation were found to be related to higher wellbeing in our study. In the overall sample, the occupation types 'having visitors, playing games, physical exercise or sports, activity related to the past, and conversation' had the strongest relationship with wellbeing. 'Doing domestic tasks, creative activities and being busy with the mind' were also related to wellbeing but at a somewhat lower level. 'Eating or drinking, and listening to music or watching TV' only had a small positive relationship with wellbeing.
These results reveal the need for residents to stay in touch with their relatives and friends, or other persons that specifically come to visit them and give them personal attention, at least for residents with mild to moderately severe dementia. They also imply that active stimulation of residents with dementia is desirable. However, the observed residents mainly spent their time in types of occupation that were not highly linked to higher wellbeing, implying that there is room for improvement.

Occupation and wellbeing for people at different stages of dementia
The relationship between types of occupation and wellbeing was found to vary among people at different stages of dementia. In people with very severe dementia, 'eating or drinking' seemed to be more important for their wellbeing than in other resident groups. Perhaps this results from the assistance that is often needed with eating and drinking for the wellbeing of people with severe dementia, which creates a moment of intimate contact with the caregiver. 'Activities that related to the past' were also of great importance in this resident group. Additionally, this group benefitted from 'looking around with attention', in other words, being passively involved. Whereas in the theory of person-centered care, passive involvement is perceived as a signal for poor quality of care, as a missed opportunity to actively engage residents in occupation potentially increasing wellbeing (Brooker & Surr, 2005).
The occupation types 'conversation, having visitors, and physical exercise or sports as well as sleeping', were less important for residents with severe dementia. Interestingly, 'doing domestic

tasks' were found to be mainly beneficial for the residents with moderate to severe dementia. The findings indicate that different types of occupation are important for residents at different stages of dementia, and underline the importance to identify the resident's functioning level. When the condition progresses, care staff and family must re-discover what types of occupation are suitable for the person with dementia and discuss how to organize these activities.

Wellbeing-related occupation versus high and low potential occupation types

We noticed that not occupation types that were defined as high potential occupation had a positive relationship with wellbeing: 'stimulating the senses, attention for an object, beauty activities, and religious activities' had no relationship with wellbeing. As described before, 'looking around with attention' was related with higher levels of wellbeing in people with severe dementia. Moreover, 'receiving physical care' was associated with lower wellbeing scores. This latter relationship was stronger for people at further stages of dementia. The fact that these groups of residents were found to suffer from more behavioral symptoms and physical impairments – often leading to more complex care - than residents with mild to moderate dementia, might explain these results. One can also imagine that receiving physical care becomes less pleasant for people with more severe dementia because they often have difficulty in understanding what is asked from them or are less able to express discomfort or pain during this care. These results suggest that the classification in high and low potential types of occupation can be deceptive, and that care staff should be aware of the individual needs and preferences in order to maximize wellbeing by involving residents in occupation.

Evaluation of the new observation instrument

In this study, a new observation instrument was used to measure daily occupation of care home residents with dementia. Given the rising interest in this aspect of dementia care, the need arose for a reliably yet easy to use and low cost instrument to monitor occupation. To our knowledge, we were the first to use the regular care staff as observers for activity involvement, that were only shortly trained. Given the fact that the conclusions of our study findings are consistent with previous research considering the prevailing occupation types in long term care homes, and the impact on wellbeing, we see potential in this research method. However, some limitations have to be mentioned. Self-evidently, we found differences in occupation patterns between day and evening shifts. Therefore, it is recommended that in future research, a clear choice is made what time of day is to be observed. Furthermore, the observers reported relatively high involvement in all different types of occupation. It is possible that they were not able to choose between types of occupation and therefore selected several types of occupation instead. This needs to be studied in more detail. Inter- and intra-reliability tests should also be performed to further investigate the psychometric properties of the instrument. Also, although a large data source of observations was generated (n=4072), the observations were performed in a relatively small sample of residents (n=171). A larger study sample will lead to better generalizable results. Furthermore, the list of occupation types that were defined can be improved. We found that the descriptions of certain occupation types could be confusing (such as the description

'having fun' for the occupation type 'playing games'). Also, the list of occupation types was not complete, illustrated by the fact that 'having visitors' was separately mentioned by the observers Further specification of the instrument therefore seems to be appropriate.

Conclusion and recommendations

Concluding from above, the daily occupation levels of care home residents living with dementia might have been increased over the last years, but these residents are still mostly involved in passive types of occupation. Various occupation types were related to higher wellbeing, which differed across residents at different stages of dementia. Overall, the most beneficial occupation types in terms of wellbeing, were observed far less frequently than occupation types that were less important for wellbeing. This suggests that there is room for improvement to increase wellbeing among people with dementia living in care homes.

An educational program that equips staff with the knowledge and skills to offer or organize types of occupation that suit the preferences and stage of dementia of individual residents, and integrate (the facilitation of) wellbeing enhancing occupation into their care tasks might facilitate higher involvement in wellbeing enhancing occupation (Smit et al., 2017). Also, since having visitors and occupations that require active assistance of the social environment are strongly related to their wellbeing, the involvement of residents' family might bring the care sector an important step further in increasing occupation and wellbeing amongst long-term-care home residents with dementia.

This study provides ground that regular care staff are able to observe their residents occupation and wellbeing for monitoring purposes. Although more research is needed to clarify its reliability and validity, and further fine-tuning is needed concerning the occupation types, the instrument seems promising.

Conflict of interest

None.

Ethics approval and consent to participate

For this study, the usual daily practice in nursing home care for people with dementia was studied without disturbing the residents in any way. Data of residents were collected through observational questionnaires by the regular care staff and processed anonymously. The Dutch medical-ethics committee METiGG declared that this study did not come within the scope of the Medical Research Involving Human Subjects Act (WMO) and therefore needed no approval.

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Chapter 6 – The relationship between small scale care and activity involvement of residents with dementia.

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Seize the day!

Abstract

Background Nursing home care for people with dementia is increasingly organized in small scale care settings. This study focuses on the question how small scale care is related to the overall activity involvement of residents with dementia, and their involvement in different types of activities. As several studies have indicated, activity involvement is important for the quality of life of residents.

Methods Data were derived from the first measurement cycle (2008/2009) of the Living Arrangements for Dementia study, in which 136 care facilities and 1327 residents participated. The relationship between two indicators of small scale dementia care (group living home care characteristics, and the total number of residents with dementia in the facility) and activity involvement (Activity Pursuit Patterns of the RAI-MDS) were studied with multilevel multiple regression analyses. All analyses were adjusted for the residents' age, gender, neuropsychiatric symptoms and ADL dependency.

Results Residents of care facilities with more group living home care characteristics were more involved in overall and preferred activities. Furthermore, they were involved in more diverse activities. Overall, no relationship was found between the number of residents at the facility and activity involvement.

Conclusions These results indicate that small scale dementia care has a positive effect on activity involvement of residents. The current study also sheds light on the lack of activity involvement of many residents with dementia, especially those of higher age, male gender and with higher dependency.

Introduction

In many Western countries nursing home care for people with dementia loses its institutional character. It is increasingly recognized that nursing home units should have a homelike atmosphere, since residents with dementia can live several years in a care facility and benefit from a familiar environment (Moise, Schwarzinger and Um, 2004). Residents with dementia should be able to bring at least some of their personal possessions and enjoy some privacy when they choose to. In several countries, nursing home organizations try to cover these needs for familiarity by providing group living home care (Verbeek *et al*., 2009). In the Netherlands, about 25% of the nursing home care for people with dementia was organized in group living home facilities in 2010 (Aedes-Actiz, 2011).

In Dutch facilities where group living home care is provided, residents live together in small groups, usually consisting of six to eight people. The personal care is integrated into daily routines, which means that care staff performs care tasks as well as domestic, social and recreational tasks. Together with the staff, residents form a substitute household with normal household activities. The daily lives of the residents are kept as 'normal' as possible (Te Boekhorst *et al*., 2007). Traditionally, group living home care in the Netherlands was provided within small archetypical (house-like) facilities. For some years now, group living home care is also provided on a larger scale. Several regular nursing homes have transformed their traditionally large dementia units into smaller units where group living home care is provided. Also many new facilities have been built that offer group living home care on a larger scale, with sometimes more than 150 residents with dementia in total. Contrary to most other countries that offer this type of dementia care, group living home

facilities in the Netherlands are meant to serve as a complete substitute for regular nursing home care instead of an intermediate between home care and the nursing home (Verbeek *et al*., 2009).

The emphasis on daily life and a familiar, homelike and relatively small environment are assumed to be better suited to the residential requirements and complex needs of people with dementia (Hammer, 1999). However, there is still a lack of evidence on the effects of such an environment on residents' quality of life. Day *et al*. (2000) found a homelike environment and small group sizes to be related to several positive outcomes like higher emotional well-being, pleasure, and social interaction among residents and with the care staff, and less anxiety, agitation, and depression. Yet these findings were often generated from anecdotic research, or could also be attributed to staff characteristics (Fleming and Purandare, 2010). Two Dutch studies on the effect of group living home care compared with traditional nursing home care found limited positive effects with respect to some subdomains of residents' quality of life (Te Boekhorst *et al*, 2009), but no effects on overall quality of life (Verbeek *et al*., 2010). Both research groups however found a modest positive effect of group living home care on the subdomain 'having something to do'. Although the operalization of this subdomain is more directed at measuring whether or not residents are able to amuse themselves than their involvement in activities, the results suggest that residents of group living care facilities might be more involved in activities than residents of more traditional nursing home facilities.

Activity involvement is important for the wellbeing of people with dementia. Especially activities that are tailored to the individual needs and preferences are expected to contribute to quality of life (Vernooij-Dassen *et al*., 2010). Research findings show several positive outcomes of activity involvement such as more positive affect, less depressive symptoms, elevated interest and alertness, less boredom, higher nutrition intake and decreased use of psychotropic medications (e.g. Brooker, Wooley and Lee, 2007; Schreiner *et al*., 2005; Verkaik *et al*., 2011; Volicer *et al*., 2006). The lack of activity involvement is related to several adverse outcomes: a loss of physical function, social isolation, neuropsychiatric symptoms and poor quality of life (Kolanowski, 2006). It is even suggested that the lack of activity involvement results in what is called 'excess disability', caused by atrophy of skills and functional capacities (Wells & Dawson, 2000). Despite these findings, activity involvement is still found to be a large unmet need of long term care residents with dementia (Hancock *et al*., 2006; Orrell *et al*., 2008).

The indication of higher activity involvement in small scale group living home care facilities is remarkable, since an important subject of discussion in the Netherlands is the activity involvement of residents with dementia in group living homes as compared with those receiving traditional nursing home care. Due to the strong emphasis on a homelike environment with normal household activities in group living home care facilities, family caregivers sometimes experience that there are too few activities and other services available for the residents. The smaller number of residents of archetypical group living home care facilities might also play a role in this, since providing care on a small scale makes it financially more difficult to offer additional services or organize extra activities outside the living rooms of the care units. Furthermore, some family caregivers argue that residents are bored because of the limited amount of time the care staff is able to provide activities next to their many other tasks (Verbeek, 2011). Also care managers and professionals sometimes raise questions about the activity offer in small group living home care facilities. Some of them wonder whether there is enough variation in activities to suit the individual needs and preferences of every resident in these facilities.

The limited research that is available on the relationship between small scale dementia care – considering both characteristics of group living home care and a small number of residents – and activity involvement is ambiguous. In a US study on activity involvement of residents of a small

homelike dementia care facility, the residents were found to be hardly involved in activities (Wood *et al*., 2005). These findings must be interpreted with caution, because they are based on a single case-study design. The researchers proposed that a homelike environment might hinder nursing staff to recognize the need for activity of the residents, since the stimulating environment seemed to make them forget that people with dementia need to be actively involved in activities.

Wood *et al*. (2005; 2009) also argued that small resident groups seemed to lead to a less stimulating environment. In a more elaborative study however, Cohen-Mansfield *et al*. (2010) found nursing home residents with dementia to be socially engaged more often when they lived in small groups of 4 to 9 people. Concerning the number of residents at the total facility site, Dobbs *et al*. (2005) found no relationship between total resident number and activity involvement in nursing homes and residential care facilities. Yet, Kuhn *et al*. (2002) found that residents of small residential care facilities - 10 to 28 residents - were less involved in activities than residents with dementia of larger sites consisting of 40 to 63 residents. It was suggested that these findings could be caused by the integral care tasks of the staff working on the smaller sites. Due to their responsibility for personal care, medication administration, food preparation, housekeeping, and social and recreational activities, staff's emphasis might be on the tasks that they find most essential, which are often the basic care needs of residents (Kuhn *et al*., 2002). This corresponds to the criticism that is sometimes heard from family caregivers in the Netherlands (Verbeek, 2011).

Since the jury is still out on activity involvement of residents with dementia within small scale care, the aim of the current study is to give further insight into this relationship. Two research questions are answered: 1. In what way is small scale care related to overall activity involvement of residents with dementia? 2. To what extent is small scale care related to the involvement of residents with dementia in different types of activities?

Methods

Design and sample

Data were derived from the Living Arrangements for people with Dementia (LAD-) study, which is an ongoing monitor on the developments and variety in Dutch nursing home care for people with dementia, and its consequences for resident quality of life, quality of care, staff ratio and staff wellbeing. Data collection takes place every two years. The design of the baseline measurement of this study has been described in detail elsewhere (Willemse *et al*., 2011).

For the present study, data on 136 long term care facilities providing nursing home care for people with dementia gathered in the first measurement cycle (November 2008 - May 2009) of the LAD-study were used. These were all non-private facilities, receiving state reimbursement by the Exceptional Medical Expenses Act (AWBZ) dependent on the referral status of the residents: a regular indication or a higher indication based on the presence of neuropsychiatric symptoms. In the Netherlands, people with a primary diagnosis of dementia are cared for at dementia-specific care units or in dementia-specific homes. Roughly five types of dementia care facilities can be distinguished which were represented in our study: traditional large scale nursing homes (n=27), nursing home units in a home for the aged (n=17), large

Table 6.1: The 20 activities listed by the Activity Pursuit Patterns of the MDS, divided in 9 categories after clustering at face validity.

Activities MDS		**Activity type**	
1 2 3	Gardening, taking care of plants Domestic tasks Cooking	1	Task related activities
4 5	Excursion or shopping Take a walk outside	2	Outdoor activities
6 7	Exercise or sports Dancing	3	Physical exercise
8	Spiritual or religious activities	4	Religion
9 10	Handwork or art Music or singing	5	Creative activities
11	Watching TV or listening to the radio	6	Leisure
12 13 14	Playing cards, games, puzzles Reading, writing, cross-word puzzles Using the computer	7	Intellectual activities
15 16	'Snoezelen' or sensory stimulation Beauty activities (manicure, hairdressing, make-up)	8	Activities with senses
17 18 19 20	Talking or making a phone call Pets Conversation groups Helping others	9	Interaction with others

nursing homes where group living home care is provided (n=31), group living homes nearby the mother facility (n=35) and stand-alone group living homes in the community (n=26).
In each participating care facility a care manager was interviewed to obtain information on the number of residents and the number of group living home care characteristics, amongst other organizational characteristics. To obtain data on resident quality of life, involvement in activities, dependency in the Activities of Daily Living (ADL), neuropsychiatric symptoms and demographics, 12 residents were randomly selected in each care facility. If there were less than 12 residents with dementia in the facility, all residents were selected. A registered nurse (RN) or certified nursing assistant (CNA) who was mostly involved with a selected resident was asked to fill out a observational questionnaire. All residents living in the participating care facilities were eligible to participate in this study. A total of 1327 observational questionnaires were filled out by care staff, resulting in a response rate of 84%.

Measures

Involvement in activities

Resident's involvement in activities was measured in three ways. Firstly, the total number of activities each resident was involved in during the past 3 days was obtained using the Activity Pursuit Patterns from the Resident Assessment Instrument Minimum Data Set (RAI-MDS). This instrument consists of a list of 20 activities (Table 6.1) for which an RN or CNA reports whether or not the resident has been involved in these activities in the past 3 days. Secondly, for each activity in which the resident was involved, the RN/CNA listed whether this was one of the resident's preferred activities or not. Thereby additional data were collected on the number of preferred

activities the residents were involved in during the past 3 days. Thirdly, to investigate the relationship between involvement in specific activity types and small-scale care, the 20 listed activities by the RAI-MDS were clustered into nine activity types (Table 6.1). Clustering was based on face validity. The authors independently clustered the activities into activity types. Items that were disagreed upon were discussed until consensus was reached. It is important to note that the clustering in activity types brings along validity problems in terms of number of items per activity type and overlap of construct. Therefore, these results of the different activity types should not be compared with each other. It is only possible to look at the relationship of each separate activity type and small-scale care.

Indicators of small-scale care

Although the participating care facilities represented five types of long term dementia care, there was large overlap in organizational characteristics between the different types of facilities, as well as a large variation in organizational characteristics within the types of facilities. This makes it invalid to compare the different care types when studying the effect of small-scale care on activity involvement of residents. We have to take the actual implementation of care characteristics into account (Smit *et al.,* 2011).

The relationship between small-scale dementia care and activity involvement was therefore studied with indicators of small-scale care. As a first indicator, the amount of group living home care characteristics that were integrated in all 136 care facilities were studied. Data on this indicator were obtained by the Questionnaire 'Group Living Home Characteristics' (Te Boekhorst *et al*., 2011). This questionnaire was based on the statements of a Concept Map concerning the ideals of group living home care (Te Boekhorst *et al*., 2007). The response-categories have a 5 point Lickert scale format. A principal axis analysis showed one factor with relatively high loadings (>0.4) of 14 items (Chronbach's α = .87). Examples of items are: Living rooms have a homelike atmosphere, Dinner is prepared in the kitchen of the living rooms, Nursing staff does housekeeping, and Residents can get out of bed whenever they want. The scale ranges from 0 to 56 with a higher score indicating more characteristics of group living home care.

As a second indicator, the number of residents per care unit was measured. However, since the number of residents per unit was highly correlated with the Questionnaire 'Group Living Home Characteristics' (r=.69), this indicator was excluded from analysis. Last, the total number of people with dementia in the care facility was registered.

Resident characteristics

To adjust for differences in demographic characteristics and functional status of the participating residents, the demographics age and gender were assessed. Furthermore, data on ADL dependency was obtained with use of the KATZ inventory (Katz, 1983), ranging from 1 to 7, with a higher score indicating more dependency in the activities of daily living. The KATZ has good psychometric properties (Cronbach's α = .91). Neuropsychiatric symptoms were measured using the NPI-Q (Kaufer *et al*., 2000; De Jonghe *et al*., 2003; Cronbach's α = .78), with a range of 0 to 36 and a higher score indicating more neuropsychiatric symptoms.

Table 6.2: Background characteristics and activity involvement of nursing home residents (1327)

Resident characteristics	**M**	**SD**
Age (41-103)	83.5	7.82
% female	76.9	-
NPIQ (0-34)	11.18	6.82
KATZ (1-7)	5.41	1.61
Activity involvement of residents		
Number of activities involved in during the past 3 days (0-16)	3.87	3.06
Number of preferred activities involved in during the past 3 days (0-14)	2.91	2.80
% of residents during the past 3 days involved in:		
Gardening, taking care of plants	3.5	-
Domestic tasks	20.1	-
Cooking	8.3	-
Excursion or shopping	12.8	-
Take a walk outside	26.4	-
Exercise or sports	16.7	-
Dancing	5.6	-
Spiritual or religious activities	22.4	-
Handwork or art	7.1	-
Music or singing	43.5	-
Watching TV or listening to the radio	59.3	-
Playing cards, games, puzzles	20.9	-
Reading, writing, cross-word puzzles	19.9	-
Using the computer	0.6	-
'Snoezelen' or sensory stimulation	9.6	-
Beauty activities (manicure, hairdressing, make-up)	20.8	-
Talking or making a phone call	54.8	-
Pets	10.0	-
Conversation groups	16.6	-
Helping others	10.2	-

Notes: NPIQ, Neuropsychiatric Inventory Questionnaire; KATZ, KATZ inventory for ADL dependency.

Analysis

Multiple multilevel linear regression analyses were performed to study the relationship between the indicators of small-scale dementia care and the number of activities the residents were involved in during the past three days (in total and preferred activities). In model 1, the analysis with the indicators of small-scale care as predictors, and the number of (preferred) activities as outcome was performed. In model 2, all resident characteristics (age, gender, neuropsychiatric symptoms and ADL dependency) were added to the analysis as possible confounders.

Multiple multilevel logistic regression analyses were performed to study the relationship between the indicators of small-scale care and the types of activities residents were involved in. For each of the nine activity types, a dichotomous variable was computed that said whether the resident was involved in this activity type or not. Model 1 concerns the unadjusted effects of indicators of small-scale care, separately for each type of activity as outcome. Model 2 concerns the effects of indicators of small-scale care adjusted for the potential confounding variables age, gender, neuropsychiatric symptoms and ADL dependency. All analyses were performed in MLwiN 2.21.

Results

Resident characteristics

The study sample had a mean age of 83.5 (SD=7.8; Table 6.2). Approximately 77% of the nursing home residents was female. The sample scored high on the KATZ ADL inventory (M=5.4, SD=1.6), meaning that the residents needed help in almost all domains of daily performance. The mean score on the NPI-Q scale for neuropsychiatric symptoms was 11.2 (SD=6.8).

On average, the residents were involved in 3.9 activities in general (SD=3.1, range 0-16)), and in 2.9 activities that they preferred (SD=2.8, range 0-14) during the past 3 days, although the large standard deviations indicate much inter-individual variety. Concerning the involvement in types of activities, most residents were involved in interaction with others (60.8% of the residents), leisure activities (59.3%) and creative activities (45.7%) during the past 3 days. Less residents were involved in other activity types during the past 3 days, varying from 20 to 33 percent per type.

Description of care facilities

There was much variety between the participating care facilities concerning the indicators of small scale care. The arrangements had a mean score on the Characteristics of Group living home care questionnaire of 30.7 (SD=10.9). Their average number of residents per unit was 9.2 (SD=3.8), and the average number of residents in total was 44.6 (SD=39.4).

Small-scale dementia care and activity involvement

Unadjusted multiple multilevel linear regression analysis showed a significant relationship between the score on the Questionnaire 'Group Living Home Characteristics' and the overall activity involvement of residents with dementia (B=.066, p<.001; Table 6.3). No relationship was found for the total number of residents at the facility site and overall activity involvement. In adjusted analysis, group living home care characteristics were still related to activity involvement at a p<.001 level (B=.053). The control variables age, gender, neuropsychiatric symptoms and ADL dependency were also highly related to activity involvement: lower age, female gender, less neuropsychiatric symptoms and low ADL dependency corresponded with more activity involvement.

Similar results were found for the involvement in preferred activities (B=.047, p<.001 for Group Living Home Characteristics in unadjusted analysis and B=.038, p<.01 in adjusted analysis; no significant relationship for number of residents). These results indicate that residents of care facilities with more characteristics of group living home care, are more involved in overall and preferred activities than residents receiving long term care with less characteristics of group living home care.

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Number of preferred activities involved in during the past 3 days (0-14)	2.91	2.80
% of residents during the past 3 days involved in:		
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Domestic tasks	20.1	-
Cooking	8.3	-
Excursion or shopping	12.8	-
Take a walk outside	26.4	-
Exercise or sports	16.7	-
Dancing	5.6	-
Spiritual or religious activities	22.4	-
Handwork or art	7.1	-
Music or singing	43.5	-
Watching TV or listening to the radio	59.3	-
Playing cards, games, puzzles	20.9	-
Reading, writing, cross-word puzzles	19.9	-
Using the computer	0.6	-
'Snoezelen' or sensory stimulation	9.6	-
Beauty activities (manicure, hairdressing, make-up)	20.8	-
Talking or making a phone call	54.8	-
Pets	10.0	-
Conversation groups	16.6	-
Helping others	10.2	-

Notes: NPIQ, Neuropsychiatric Inventory Questionnaire; KATZ, KATZ inventory for ADL dependency.

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Small-scale dementia care and involvement in types of activities

Logistic regression analyses showed that residents of facilities with more group living home characteristics, were more involved in task related activities, outdoor activities, leisure activities, physical exercise and interaction with others (B ranging from .029 to .051, p<.01 to .001 in unadjusted analysis and B ranging from.024 to .047, p<.01 to .001 in adjusted analysis; Table 6.4). The number of residents of the total facility site only predicted the involvement in intellectual activities (unadjusted: B=-.010, p<.001; adjusted B=-.009, p<.001), indicating that residents of larger facilities are less involved in intellectual activities.

Table 6.3: The relationship between indicators of small-scale dementia care and resident's involvement in (preferred) activities during 3 days.

Dependent variables	**Number of total activities involved in**		**Number of preferred activities involved in**	
Independent variables	*B*	*SE*	*B*	*SE*
Model 1				
Constant	2.086	0.420	1.686	0.379
Group living characteristics	0.066***	0.011	0.047***	0.010
Number of residents at facility	-0.004	0.003	-0.004	0.003
Model 2				
Constant	7.588	0.997	6.826	0.913
Group living characteristics	0.053***	0.011	0.032**	0.010
Number of residents at facility	-0.004	0.003	-0.004	0.003
Age	-0.033***	0.010	-0.025**	0.009
Gender (female)	0.774***	0.186	0.670***	0.172
NPIQ neuropsychiatric symptoms	-0.037**	0.012	-0.337*	0.128
KATZ ADL dependency	-0.529***	0.051	-0.552***	0.047
R^2 model 1	.368		.292	
R^2 model 2	.449		.427	

* p<0.05. ** p < 0.01, *** p < 0.001

Notes: Group living home characteristics, 14-item version of the Questionnaire 'Group Living Home Characteristics', NPIQ, Neuropsychiatric Inventory Questionnaire; KATZ, KATZ inventory for ADL dependency. NB: The explained variance (R^2) concerns the variance between the participating care facilities.

Table 6.4: The relationship between indicators of small-scale dementia care and resident's involvement in activity types during 3 days.

Dependent variables	**Task related activities**		**Outdoor activities**		**Religion**		**Leisure**		**Physical exercise**	
Independent variables	*B*	*SE*	*B*	*SE*	*B*	*SE*	*B*	*SE*	*B*	*SE*
Model 1										
Constant	-2.716	0.327	-2.381	.326	-1.569	.353	-.511	.275	-2.402	.346
Group living characteristics	.051***	.009	.042***	.009	.011	.009	.031***	.007	.0.029**	.009
Number of residents at facility	-.002	.002	.003	.002	-.000	.003	-.001	.002	.002	.002
Model 2										
Constant	1.798	0.932	1.526	.826	-1.446	.896	2.940	.782	2.014	.917
Group living characteristics	.047***	.009	.036***	.009	.007	.010	.028***	.008	.024**	.009
Number of residents at facility	-.002	.002	.003	.002	-.000	.003	-.001	.002	.001	.002
Age	-.031**	.010	-.030***	.009	.001	.009	-.020**	.008	-.036***	.010
Gender (female)	.834***	.203	-.360*	.156	.561**	.186	.071	.148	.327	.189
NPIQ neuropsychiatric symptoms	-.007	0.011	.006	.010	-.021	.011	-.044*	.009	-.009	.011
KATZ ADL dependency	-.471***	.048	-.191***	.042	-.051	.045	-.222***	.043	-.262***	.046
R^2 model 1 R^2 model 2	.414 .450		.248 .268		.033 .087		.175 .225		.166 .215	

Dependent variables	Creative activities		Intellectual activities		Activities with senses		Interaction with others	
Independent variables	*B*	*SE*	*B*	*SE*	*B*	*SE*	*B*	*SE*
Model 1								
Constant	-.453	.253	-.700	.265	-1.104	.268	-.377	.263
Group living characteristics	.012	.007	.013	.007	.004	.007	.031***	.007
Number of residents at facility	-.002	.002	-.010***	.002	-.001	.002	-.002	.002
Model 2								
Constant	.796	.743	1.029	.811	-2.327	.829	.839	.777
Group living characteristics	.011	.007	.008	.008	.006	.007	.028***	.008
Number of residents at facility	-.002	.002	-.009***	.002	-.002	.002	-.002	.002
Age	-.012	.008	-.002	.009	-.005	.009	-.007	.008
Gender (female)	.609	.146	.317*	.160	1.147***	.196	.054	.149
NPIQ neuropsychiatric symptoms	-.018*	.009	-.037***	.010	-.007	.010	-.013	.009
KATZ ADL dependency	-.090*	.039	-.239***	.041	.144**	.046	-.291***	.044
R^2 model 1 R^2 model 2	.091 .106		.346 .084		.027 .142		.229 .000	

* p<0.05. ** p < 0.01, *** p < 0.001

Notes: Group living home characteristics, 14-item version of the Questionnaire 'Group Living Home Characteristics', NPIQ, Neuropsychiatric Inventory Questionnaire; KATZ, KATZ inventory for ADL dependency. NB: The explained variance (R^2) concerns the variance between the participating care facilities.

Table 6.5. The mean percentages of residents that were involved in activity types in care facilities for people with dementia (N=136), arranged in quartiles according to the score on the Group living home characteristic (GLHC) questionnaire and the number of residents at the facility site.

	Group living home characteristics				**Number of residents at facility site**			
Activity type	**Q1#**	**Q2#**	**Q3#**	**Q4#**	**Q1†**	**Q2†**	**Q3†**	**Q4†**
Task related activities	12.25	18.88	24.60	39.97	35.21	27.70	18.70	19.08
Outdoor activities	18.35	24.19	29.08	39.96	35.12	24.52	27.01	28.00
Religion	17.85	25.08	24.94	21.54	27.32	16.41	23.55	22.13
Leisure	53.91	53.14	57.90	71.88	63.39	61.39	57.58	57.62
Physical exercise	15.84	13.73	19.50	26.69	25.35	14.25	17.42	20.56
Creative activities	43.00	42.64	48.36	49.98	54.70	46.42	40.39	44.30
Intellectual activities	28.99	30.46	31.31	40.88	43.82	41.56	29.41	20.51
Activities with senses	26.94	28.57	23.20	30.31	29.25	30.87	27.19	23.56
Interaction with others	53.11	52.70	64.58	70.79	70.20	62.60	56.46	54.68

Care facilities divided in quartiles according to their score on the Group living home care characteristics questionnaire; Q1 represents the lowest scoring quartile ranging from 8-21, Q2 ranges from 21-33, Q3 ranges from 33-40 and Q4 represents the highest scoring facilities with a range from 40 to 52).
† Care facilities divided in quartiles according to their total resident numbers; Q1 represents quartile of facilities with the least residents ranging from 6-18, Q2 ranges from 18-30 residents, Q3 ranges from 30-61 and Q4 represents the facilities with the largest resident numbers ranging from 61 to 240).

The results on involvement in types of activities and small-scale care are illustrated in Table 6.5. This table presents an overview of the mean percentage of residents that were involved in the nine types of activities within care facilities arranged in quartiles corresponding to their scores on both the Questionnaire 'Group Living Home Characteristics' and the number of residents at the facility. For example, in living arrangements with the least group living home care characteristics, 12.3% of the residents were involved in task related activities during the past 3 days, compared to 40.0% of the residents in living arrangements with the most group living home care characteristics. And 43.8% of the residents with the least residents at the total facility were involved in intellectual activities, compared to 20.8% of the residents of the facilities with the most residents in total.

Discussion

In this study, the relationship between activity involvement of residents with dementia and two indicators of small-scale care was studied. It was found that residents of facilities with more group living home care characteristics were involved in more activities during the past 3 days. This holds true for both activities in general and activities that they preferred. Furthermore, residents of facilities with more group living home characteristics, were more involved in task related activities, outdoor activities, leisure activities, physical exercise, and interaction with others. For the other types of activities (religion, creative activities, intellectual activities and activities with senses) no differences were found. The number of residents at the total facility site was not related to the direct involvement in (preferred) activities. Concerning the involvement in activity types, it was only found that a higher number of residents at the facility was related to less involvement in intellectual activities. These results indicate that small-scale dementia care

as measured with the number of characteristics of group living home care has a positive effect on activity involvement of residents.

A first explanation of the findings might be that a homelike environment may offer more opportunities or a better ambiance for residents to be involved in small activities in the shared living room, like listening to music, watering plants, reading, cleaning, or having a group conversation. Simply surrounding residents with activities is not enough to get them engaged in activities, as was stated before by Wood *et al*. (2005). However, a stimulating environment might make it easier for care staff to offer these small activities. Small activities in the living room are important because they can be organized on a frequent basis. Therefore, it is recommended to complement large scale activities (like bingo, large holiday celebrations, and a visit to the zoo) with small activities.

Another explanation might be the small resident groups that are common in facilities that provide group living home care, illustrated by the high correlation between these characteristics that was found in our study sample. This corresponds to the findings of Cohen-Mansfield *et al*. (2010) that nursing home residents living in small groups were socially engaged more often. Smaller groups of residents might cause the staff to become better acquainted with the residents and know more about their life history and personal preferences. The smaller environment may also enable the staff to pick up signals of residents more easily that indicate the need for activity involvement. They might be less distracted by other residents or colleagues, and be better aware when residents have not been active for a long time.

The fact that care staff of facilities that provide group living home care are responsible for the activity provision is also likely to contribute to a higher activity involvement of residents. Although the responsibility for both the physical care of the residents, domestic tasks and the activity provision can be demanding (Kuhn *et al*., 2002; Verbeek, 2011), it might also lead to a higher awareness and control of the activity involvement of residents.

While staff working in facilities with a high level of group living home care are focused on providing activities in the living room, staff working in more traditional facilities might hide behind a central activity program or separate occupational therapists to fulfill the residents' needs for activities. It is also possible that care staff working in living arrangements that provide group living home care differ from regular nursing home care staff with regard to their personal characteristics (Te Boekhorst *et al*., 2008). Group living care staff might have been more extrovert or equipped with more organizational talent than staff working in facilities that provide traditional nursing home care, characteristics that can influence the activity involvement of people with dementia. The points addressed here are all hypotheses. Further research is needed to determine the exact mechanism that lies behind the effect of small-scale care on activity involvement.

Our findings are in line with those of Te Boekhorst *et al*. (2009) and Verbeek *et al*. (2010) that residents of group living homes score higher on the 'having something to do' subdomain of quality of life than residents of regular nursing homes. With regard to the results from the US research of Kuhn *et al*. (2002) and Wood *et al*. (2005; 2009), it is possible that our contradictory results are caused by international differences in dementia care or care staff. The concept of small-scale dementia care varies across countries with respect to physical setting, number of residents, resident characteristics, domestic characteristics and costs (Verbeek, 2009). Staff

working in group living home facilities in the Netherlands might be better facilitated to perform integral care tasks than staff in the US. Another explanation might be that the US findings are generated from observational data, whereas the findings of the current study are based on staff reports.

For feasibility reasons, it was not possible to perform systematic observations within this large sample of residents. This might have caused information bias. Care staff working in facilities with many characteristics of group living home care might have interpreted certain actions or behavior more easily as involvement in an activity. Moreover, because group living home care staff are responsible for activity provision themselves, they might have been better able to observe the involvement in activities than regular nursing home staff. It is hard to say to what extent this possible bias has influenced our study data. Another limitation of this study is that by using the Activity Pursuit Pattern questionnaire from the MDS-RAI, only the number of activities the person was involved in could be studied, and not the extent to which a resident was involved in this activity. Although the MDS instrument also includes a question on how much time the residents are involved in activities during the day, this question was not sensitive due to the broadness of the answer categories ranging from none, 1/3 of the day, 2/3 of the day, to almost all day. Almost all residents in our sample were involved in activities '1/3 of the day'. We therefore were restricted to the number of different activities a person was involved in. Although a person might be involved in only one activity, it is possible that he was involved in this for a long time, or for several times during the past 3 days. Therefore, the question whether small-scale dementia care is related to the actual time that residents are involved in activities, remains unanswered. Finally, this study has a cross sectional design, so an actual causal relationship between small scale care and activity involvement cannot be demonstrated.

The current study provides some evidence to question the national criticism on activity involvement in small scale care facilities. Small-scale care seems to offer more opportunities to involve residents in activities, and does not limit the activity types residents are involved in. In addition, this study provides further insight in the amount and types of activities people with dementia living in long term care facilities are involved in. On average, the residents were involved in almost 4 activities in three days, and in 3 activities that they preferred doing. There was much inter-individual variety however: 15% of the residents was not involved in any of the 20 activities at all during the past three days. 32% of the residents was not involved in interaction. This suggests that people with dementia are still hardly involved in activities. Considering the relationship of activity involvement with indicators of quality of life and possibly with excess disability, it is important to set the agenda for more activity involvement in dementia care practice.

This study also showed that in addition to the way in which dementia care is organized, individual resident characteristics play an important role in their activity involvement. The low activity involvement of people with dementia with severe cognitive or functional impairment has been described before by Kuhn, Fulton & Edelman (2004). They pleaded for more one-to-one and small group approaches to promote engagement and maximize their quality of life. Based on our study findings, it appears that higher dependent residents are still less involved in activities when they receive small scale dementia care. It was found that neuropsychiatric problems and ADL dependency, as well as age and gender of residents predicted activity involvement often stronger than the indicators of small scale care. These findings indicate that residents of higher age, male residents, residents with more challenging behavior and more ADL dependency should receive specific attention when it comes to activity involvement, despite the type of care they receive. Extra effort should be made to explore their preferences and abilities in order to address their specific need for activation and purpose.

Conflict of Interest
None.

Description of author's roles
DS analyzed the data and drafted the manuscript. JdL helped to draft this manuscript, and BW with analyzing the data. AMP helped to draft this manuscript, checked the analyses and is principal investigator of the LAD-study. All authors contributed to the design of the LAD-study. All authors read and approved the final manuscript.

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Chapter 7 – Predictors of activity involvement in long-term dementia care homes: a cross sectional study

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Seize the day!

Abstract

Background Despite the finding that involvement in activities is one of the most important needs of residents with dementia living in care homes, care facilities struggle to fulfill this need. Over the years, various factors are suggested which may contribute to or disable activity provision in dementia care homes. These include limited financial resources, task oriented staff and disease-related characteristics of residents. This study aims to further clarify which of these factors predict higher activity involvement.

Methods Data were derived from the second measurement (2011) of the Living Arrangements for people with Dementia study. 1,218 people residing in 139 dementia care homes were involved. 40 predictors of higher involvement were studied. Multilevel backward regression analyses were performed.

Results The most important predictors of higher involvement were: absence of agitation, less ADL dependency, and a higher cognitive status of the residents, higher staff educational level, lower experienced job demands by care staff and a smaller number of residents living in the dementia care units of a facility. More social supervisor support as perceived by staff was found to predict less activity involvement.

Conclusions To increase the activity involvement of care home residents with dementia it seems vital to: 1) reduce staff's experienced job demands; 2) elevate their overall educational level; 3) train staff to provide suitable activities, taking account of the behavior and preserved capabilities of residents; and 4) foster transition towards small-scale care. In order to achieve these aims, care organizations might need to evaluate the use of their financial means.

Background

The involvement in activities by people with dementia living in long-term care homes is frequently associated with higher quality of life outcomes[1]. Several intervention studies have shown that involvement in recreational, vocational or leisure activities could increase positive mood or decrease behavioral symptoms during and directly after involvement, and might also have beneficial effects on these outcomes over time[2,3,4] .

Moreover, activity provision is increasingly cited as an indicator of resident and family satisfaction with care[5]. A literature review reveals that besides the management of behavioral symptoms, involvement in meaningful activities and social interaction were the most important needs for long-term care residents with dementia - as described by care staff, family caregivers and people with dementia themselves[6]. In a modern society, enabling people to do what they find of value is perceived as a basic human right for the aging population, including people with dementia[7].

Yet, despite these urgent calls for making activity involvement one of the core elements of long-term care provision, many dementia care homes struggle to reach an appropriate level of activity involvement among their residents[8,9,10]. The dementia care home is often described as a place of boredom where residents do little besides sleeping, eating, looking around, and having a conversation[11,12,13]. In our previous research, we found that on average, residents were involved in activities for less than one hour a day besides having a conversation, listening to music or the radio, or watching TV[14].

Knowing the barriers and facilitators of activity involvement in dementia care homes

might help to find solutions for the unfulfilled need for activities among residents with dementia. Over the last two decades, many factors that predict activity provision in long-term dementia care have been suggested and studied (see Appendix 1). These potential predictors of activity involvement can be grouped into characteristics of 1) *residents with dementia*, 2) *finances, staff ratio and staff educational level*, 3) *modern versus traditional care culture within the care home*, 4) *job strain as perceived by care staff*, 5) *the physical care environment*, and 6) *the organization of activities*. These are discussed briefly below.

Characteristics of the *residents with dementia* include disease-related characteristics and sociodemographic characteristics. Examples are physical and cognitive impairment, challenging behaviors (e.g. agitation, apathy, anxiety and depression)[15-25], age, gender and length of stay in the care home[16,22,26,27].

With regard to the characteristics of *finances, staff ratio and staff educational level,* it is assumed that the limited financial resources available to care homes, resulting in a low staff ratio and a low staff educational level, or little knowledge of dementia, negatively impact the activity involvement of residents[12,27-34]. A stable care team with sufficient knowledge of dementia care is likely to result in higher activity involvement[35], as well as the availability of professional treatment for residents (for example, assessment for depression by a mental health professional)[16].

Examples of characteristics of *a modern as opposed to a traditional care culture* in a care home, are the presence of a well implemented philosophy on quality care and a transformational leadership style. These factors were found to enhance activity provision[4,36]. Delivering person-centered care - requiring staff to gain knowledge of the biography and psychological needs of the residents in order to adjust their approach and care to the individual care recipient – and family involvement[16,17] are also mentioned as factors that stimulate activity provision in long-term dementia care[33,37]. This contrasts with the traditional focus on routines, in which priority is given to care tasks over psychosocial needs[21,27,33,38]. The traditional higher administration of psychotropic drugs and use of physical restraints for the treatment of challenging behavior are thought to negatively influence the activity involvement of residents[15,16,25].

Job strain as perceived by care staff[12,16,33,35,37] is the result of a complex combination of factors, such as the physical and emotional care needs of residents, staffing levels, support from colleagues and supervisor, decision authority, and the feeling of being competent to care for their care recipients[39,40]. Examples of perceptions of strain that were found to result in limited activity provision to residents, are a lack of conviction of being capable of involving residents in activities[15,17],and a perceived lack of support from supervisors and colleagues with regard to spending time on providing activities[28].

With regard to characteristics of the *physical care environment,* a small-scale group living home environment, or a recognizable or homelike environment with opportunities for residents to be engaged in normal household activities, was found to stimulate activity involvement in several studies[41-45].

The organization of activities refers to differences in the activities offered by care homes. Providing smaller and individual activities that are tailored to the needs, skills and preferences of residents seems to enhance their engagement in activities[24,46-49]. Presumably, this should not solely be the task of activity or recreational staff[3,16,27,28,50]. Conversely, offering activities in the form of standard, centrally provided activity schedules for large resident groups is thought to predict lower activity involvement [15,20,51].

In conclusion, many factors may have a disabling or enabling impact on the involvement of people with dementia living in care homes. However, the factors mentioned in the literature are often only suggested, have been studied but not scientifically tested, or have been studied within small sample sizes. It is also unclear how the various factors relate to each other. In the

current study, we further clarify how the following characteristics relate to higher activity involvement: characteristics concerning 1) *residents with dementia,* 2) *resources in terms of finances, staff ratio and educational level,* 3) *modern versus traditional care culture,* 4) *the job strain perceived by care staff*, 5) *the physical care environment* and 6) *the organization of activities*. The findings of this study may provide care organizations with pointers to address their residents' need for occupation.

Methods

Design and sample

Design

This study has a cross-sectional design. Observational data were used from questionnaires and interviews that were obtained in the second measurement cycle (January – June 2011) of the Living Arrangements for People with Dementia (LAD-) study. The LAD-study is an ongoing study on developments in Dutch nursing home care for people with dementia and the consequences of environmental and organizational characteristics - such as group living home care, person-centeredness and staffing levels - for residents, family and staff wellbeing. Data collection takes place every two years. The design of the first measurement cycle of this study has been described in detail elsewhere[52]. In Figure 7.1, the design of the 2nd measurement cycle of the LAD-study is shown schematically.

The reason we used data from the second measurement cycle is that in the first cycle, solely data on residents' involvement in types of activities were collected and not on time spent. Previous research pointed to the need to also collect data on time spent on these activities[44]. For this purpose, the measurement instrument was expanded in the second cycle.

Care home settings

Data from 144 long-term-care facilities providing nursing home care for people with moderate to very severe dementia were gathered. In the Netherlands, people with a primary diagnosis of dementia are cared for on dementia-specific care units or in dementia-specific care homes. The participating living arrangements represented the five types of nursing home care that are provided in the Netherlands: traditional large-scale nursing homes (n=28), nursing home units in homes for the aged (n=30), large-scale group-living homes (defined as group-living home care facilities with 36 or more residents with dementia; n=28), 'archetypal' small-scale group-living homes (defined as fewer than 36 residents with dementia) that solely provided group-living home care (n=28), and small-scale group-living homes that also provided other types of care at the same location, for instance care for somatic patients (n=25). In the Netherlands, small-scale group-living homes for people with dementia are designed to provide person-centered long-term care, where residents can reside until death, despite severe cognitive or physical impairments. Previous research has shown however, that residents of 'archetypal' small-scale group-living homes were less physically and cognitively impaired than residents of large-scale nursing homes on average. Furthermore, small-scale group-living home residents were sometimes transferred to regular nursing homes when their care needs increased[53,54]. The participating care homes were all state-financed.

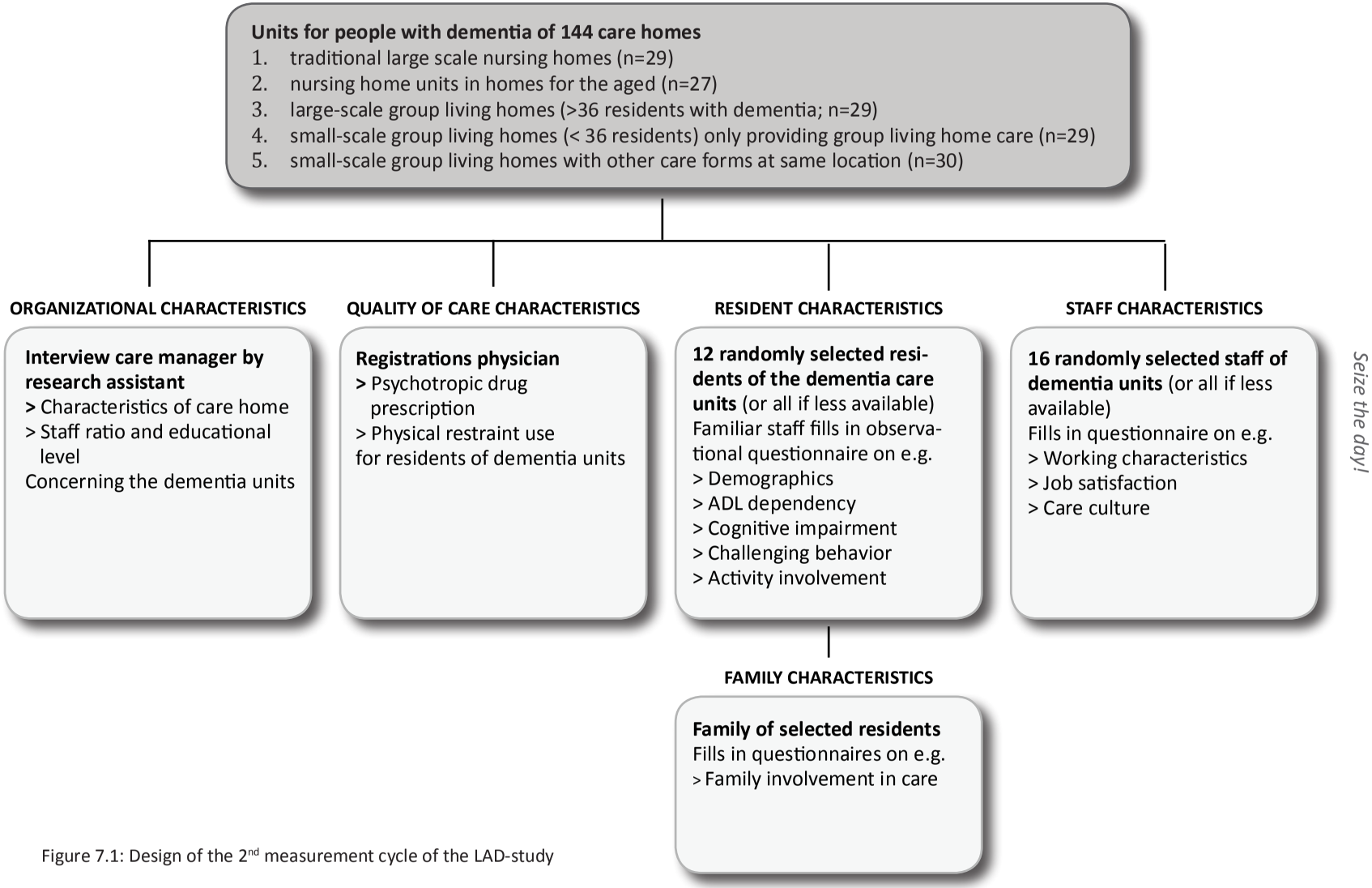

Figure 7.1: Design of the 2nd measurement cycle of the LAD-study

Data collection procedure

In each participating care home, a care manager was interviewed by a trained research assistant to obtain data on environmental and organizational characteristics as well as staff ratio of the care homes' care units for people with dementia. In each care home, the old age care physician was asked to fill out registration forms on the prescription of physical restraints as well as psychotropic drugs from the medical records of all residents residing on the dementia care units.

To gather information on the activity involvement of residents with dementia, their physical and cognitive impairment, behavioral symptoms and demographics, 12 residents from the dementia care units were randomly selected in each care home. All residents on the participating dementia units were eligible to participate. If there were fewer than 12 residents of dementia care units in a home, all residents of these units were included. A registered nurse (RN) or certified nursing assistant (CNA) who was most involved with a selected resident was asked to complete observational questionnaires. For feasibility reasons, staff could not be trained in completing these questionnaires. Therefore, the questionnaires were provided with detailed instructions on how to answer the questions of the instruments used. Staff were also invited to contact the research group for assistance at any time.

To collect data on family involvement in their relative's care, the primary family caregiver of each randomly selected resident was invited to participate in the LAD-study by completing a questionnaire.

Furthermore, 16 care staff members (i.e. nursing assistants, CNAs, RNs) who worked on the dementia care units were randomly selected in each care home to obtain information on working characteristics, job satisfaction and care culture. If there were fewer than 16 care staff members, all care staff were included. Only care staff working on a permanent basis were eligible to participate.

Measures

Dependent variable: Involvement in activities

The activity involvement of residents with dementia was measured using the Activity Pursuit Patterns from the Resident Assessment Instrument Minimum Data Set (RAI-MDS[55]). To our knowledge, no explicit data on intra- and interrater reliability are available on the Activity Pursuit Patterns[56,57]. The instrument consists of a list of 20 activities (Table 7.1) for which an RN or CNA retrospectively answers the question whether or not the resident has been involved in these activities during the past three days. To study the time of activity involvement, we expanded the original Activity Pursuit Patterns questionnaire by adding questions on how many times the person was involved in this activity during the past three days, and for how many minutes on average for each time.

Estimated times that residents were involved in any of the listed activities during the past three days were calculated (Table 7.1). It was found that RNs and CNAs sometimes reported that residents were involved in talking, music or singing, or watching television (activity number 3, 9 and 15) for very long periods, sometimes the entire time they were awake. Further investigation taught us that in some cases a resident spoke to himself the whole day, or that residents sat in a place where the radio or television was on for several hours, without actual involvement in conversation, singing, watching a television program or listening to music. Since the purpose of this study was to analyze predictors of actual involvement in

activities, these occupations were excluded from the analyses. The total duration of involvement was therefore calculated on the basis of the time residents were involved in the 17 remaining activities during the past three days.

Table 7.1: The 20 activities listed by the Activity Pursuit Patterns of the MDS-RAI and estimated time of involvement of study population (n=1218) during three days.

Activities MDS-RAI		**Range time involved**	**Mean**	**SD**
1	Playing cards, games, puzzles	0-420	18.25	44.60
2	Using the computer	0-90	0.16	3.35
3	*Talking or making a phone call**	*0-600*	*45.15*	*66.21*
4	Handwork or art	0-360	6.66	28.42
5	Dancing	0-120	1.61	9.70
6	Exercise or sports	0-180	9.82	21.04
7	Gardening, taking care of plants	0-120	1.07	7.59
8	Helping others	0-90	1.99	8.69
9	*Music or singing**	*0-540*	*30.91*	*52.92*
10	Pets	0-360	4.40	20.43
11	Reading, writing, cross-word puzzles	0-630	17.72	52.99
12	Spiritual or religious activities	0-360	14.76	35.82
13	Excursion or shopping	0-720	15.87	52.42
14	Take a walk outside	0-540	25.38	50.08
15	*Watching TV or listening to the radio**	*0-2100*	*140.43*	*205.93*
16	Domestic tasks	0-370	6.84	24.12
17	Cooking	0-300	5.57	19.31
18	Conversation groups	0-360	6.42	22.36
19	'Snoezelen' or sensory stimulation	0-420	5.34	22.57
20	Beauty activities (manicure, hairdressing, make-up)	0-240	9.74	19.30

* excluded from analyses for reliability reasons (suspected confusion between passive and active involvement)

1) Characteristics of residents with dementia

The characteristics age, gender, having a life partner, length of stay in the care home, ADL dependency, cognitive state and behavioral symptoms were assessed as potential predicting factors relating to residents. Based on the hypotheses that a recent transfer to a long-term-care home might positively or negatively influence activity involvement[9,16], length of stay was dichotomized in shorter (< 6 months) and longer length of stay (>6 months).

ADL dependency was measured with the Katz inventory[58] (Cronbach's α = .918 in this sample; range 1-7). The score on this scale was treated as a continuous variable, with a higher score indicating more ADL dependency. To specifically study the influence of mobility on activity involvement, the item of being able to transfer was also studied separately. For this purpose, this item was dichotomized in 'yes' (transferring independently with or without instrumental aids), and 'no' (hardly or not being able to transfer independently. Behavioral symptoms were measured using the Neuropsychiatric Inventory[59,60] (NPI-Q; Cronbach's α = .743 in this sample; range 0-36). The total score on this scale was treated as a continuous variable, with a higher score indicating more behavioral symptoms. In the NPI-Q, the occurrence of symptoms of delusions, hallucinations, irritableness, eating disorders, sleeping disorders, disinhibition, euphoria, repetitive behavior, depression, apathy, agitation, and anxiety are measured. Because the latter four items were explicitly mentioned in the literature as influencing activity involvement, these

were also separately studied. All four symptoms were dichotomized in 'no' if the behavior only seldom occurred, or not at all. If they occurred on a regular basis, they were classified as 'yes'. Data on cognitive status were studied with the Cognitive Performance Scale[61] (CPS; Cronbach's α= .814 in this sample; range 0-6). The score on the CPS was studied as a continuous variable, with a higher score indicating more cognitive impairment.

2) Characteristics of financial resources, staff ratio and staff educational level
Information on staff ratio and care staff educational level was derived by obtaining the actual working schedules used in care homes. The number of working hours per week per resident during day-time was calculated, including the working hours of possible recreational workers. Information on education level was derived by calculating the percentage of the total staff ratio in which staff with education level three or higher was working. In the Netherlands, a healthcare worker's education level ranges from 1 to 5. In the Dutch education system, level 2 is equivalent to nursing assistant in the USA, level 3 to certified nursing assistant, and level 4 and 5 to registered nurse - all likewise in the USA.
The availability of (para)medics was measured as the total number of hours that (para)medics (e.g. the nursing home physician, psychologist, physiotherapist, occupational therapist, dietician) were available weekly for the dementia care units. Next, these hours were divided by the total number of residents in these units.
The average of 6 months of sick leave data concerning the dementia care units were used to indicate instability of staff and abnormalities in schedules concerning staff quantity or quality, as well as information on the number of staff vacancies per resident.

3) Characteristics of modern vs. traditional care culture
Transformational leadership, person-centered care, unity in care philosophy, psychotropic drug prescription and physical restraint use, and family's perceived involvement in care were studied as indicators of a modern (psychosocial) or traditional (medical) care home culture.
Transformational leadership was measured with a Dutch translation of The Global Transformational Leadership scale[62] (GTL), that consists of 7 items and asks staff members questions on how charismatic, innovative, supportive, empowering, encouraging and challenging their direct manager is. The measure proved to have high reliability in our sample (Cronbach's α= .955 in our sample, range 1-5).
A Dutch translation of the Person-Centered Care Assessment Tool[63] (P-CAT) was used to measure the extent to which the care staff and care home operate in a person-centered manner. It contains questions on whether residents' individual needs are inventoried daily, whether they can participate in individualized activities, and whether there is a focus on creating a calm and homelike environment. The original instrument consisted of 14 items. Factor analysis revealed that 2 items had to be left out of analyses to form a reliable scale. The scale ranges from 1 to 5 and had a Cronbach's Alpha of .806 in our sample. A higher score indicates more person-centered care.
To study whether or not care facilities operated strongly from a certain philosophy of care regarding living arrangements, we designed the Unity in Care Philosophy questionnaire[64]. This instrument consists of 7 items (Cronbach's α= .916 in our

Table 7.2: List of factors that were suggested to influence activity involvement of care home residents with dementia that were represented in the LAD-study; description of variables and measurement specifications

Proposed factor in literature	Selected variables in LAD-study	Measurement specifications
Characteristics of residents with dementia		
Age	1. Age	Years acquired by date of birth (42 to 101)
Gender	2. Gender	Male or female
Marital status	3. Having a life partner	Life partner yes or no/diseased
Length of stay	5. Length of stay	< 6 months or > 6 months
ADL dependency	6. ADL dependency	Katz ADL dependency scale (1 to 7)
Immobility	7. Immobility	Transfer-item of Katz scale was dichotomized in mobile (being able to transfer independently with or without instrumental means) and immobile (hardly or not able to transfer independently)
Cognitive functioning	8. Cognitive impairment	Cognitive Performance Scale (CPS; 0 to 6)
Behavioral symptoms	9. Challenging behavior	Short version Neuropsychiatric Inventory questionnaire (NPI-Q; 0 to 36)
depression	10. Depression	The loose NPI-Q items for depression, agitation, anxiety, and apathy were dichotomized into no or rare occurrence, and frequent occurrence.
agitation	11. Agitation	
anxiety	12. Anxiety	
passivity, apathy (loss of interest or lack of motivation)	13. Apathy	
Characteristics of resources of finances, staff ratio and educational level		
Staff ratio / shortness of time and resources	14. Staffing levels	Hours of care staff available per week per resident on dementia care units (13.86 to 30.48)
Insufficient knowledge of dementia / lack of skills / Formal staff training	15. Educational level of care staff	Percentage of scheduled care staff with education level 3 (certified nursing assistant) or higher (22.70 to 100)
Ratio receiving professional or unprofessional treatment / Involvement of physicians or paramedics in care planning	16. Availability of (para) medics	Number of available hours of (para)medic staff per week per resident of dementia care units (0 to 5.06)
Instability of care team / High staff turnover / leave of skilled staff that were not replaced	17. Number of vacancies	Number of care staff vacancies per resident of dementia unit that were not yet fulfilled (0 to 0.22)
	18. Average sick leave	Average percentage of sick leave of the past 6 months concerning staff working on dementia care units (0.82 to 17.0)
Characteristics of modern or traditional care culture of the care facility		
Strong management and leadership	19. Transformational leadership	Global Transformational Leadership (GTL) scale (1 to 5)
Person centered care / approach to people with dementia/ positive person work / insufficient attention to resident's occupational needs, initiatives and capabilities / Lack of understanding importance of occupation / Task oriented working / Prioritization of physical over psychosocial needs / Organizational routines limiting autonomy of residents/ Family involved in assessment activities	20. Person-centered care	Person-centered Care Assessment Tool (P-CAT; 1 to 5). 12 of the 14 items were used based on factor analyses: items 4 and 13 were dropped
	21. Family perceived involvement	Family Perception of Caregiver Role (FPCR) instrument (1 to 7). 23 of the 31 items were used based on factor analyses: items 3-6, 8, 13, 14 and 17 were dropped.

Philosophy of care	22. Philosophy of care	Unanimity in care philosophy questionnaire (1 to 5)
Psychotropic / anticholinergic / antipsychotic / sedative drug use	23. Psychotropic drug use	Average number of prescribed psychotropic drugs per resident (0.17 to 2.38)
Use of physical restraints	24. Physical restraint use	Average number of physical restraints applied per resident (bed rails not included; 0 to 0.74)
Characteristics of job strain as perceived by care staff		
Perceived high workload / lack of time / emotional and task related demands / work stress	25. Job demands	Work and time pressure subscale of the Leiden Quality of Work Questionnaire (LQWQ; 1 to 4)
	26. Decision authority	Decision authority subscale of the LQWQ (1 to 4)
	27. Burn-out complaints	emotional exhaustion subscale Utrecht Burn-out Scale-C (UBOS; 0 to 6)
Work satisfaction	28. Job satisfaction	Job satisfaction subscale LQWQ (1 to 4)
Perceived support of staff	29. Social support colleagues	Social support co-workers subscales LQWQ (1 to 4)
Perceived support of manager	30. Social support supervisor	Social support supervisor subscales LQWQ (1 to 4)
Competence to provide suited activities / Perceived success in treatment of residents	31. Feelings of competence	Feelings of competence subscale UBOS (0 to 6)
Characteristics of the physical care environment		
Number of residents in facility / smaller size of facility	32. Total number of residents of care home	Total number of residents of the dementia care units of care home (6 to 161)
Small scale living facility / Familiar environment / homelike environment or atmosphere / household environment / social interaction enhancing environment / small group of people	33. Group living home care characteristics	14-item version of the Questionnaire 'Group Living Home Characteristics' (0 to 56)
Characteristics of the organization of activities		
(Absence of) large group activity offer or standardized activities/ Individual and small group activity offer / lack of organized activities / activity choices / availability of various and ongoing or continuous activities / focus on everyday occupation	34. Central activity program	Are there activities organized by a central activity program, are there activities that are offered in the living rooms, and are there activities organized in the form of in clubs (more options are possible) – all variables dichotomized in yes or no.
	35. Activities that are offered in the living rooms	
	36. Activities in the form of in clubs	
Activity provision not restricted to activity workers / no specialized worker perspective	37. Activities are (also) offered by care staff	yes or no
Activities provided by recreational staff / absence of activity staff	38. Availability of recreational or activity staff	Number of available hours per week per resident of dementia care units (0 to 4.71)
Family involvement (hr/week)	39. Availability of help of family caregivers	Number of hours of help from family caregivers per week per resident (0 to 4.20)
	40. Availability of help of volunteers	Number of hours of help from volunteers per week per resident (0 to 6.67)

Notes: In this Table, only predicting variables have been included that were measured in the LAD-study. In the literature, more predictors were suggested (see Appendix 1)

sample) reflecting common philosophy of care statements. Care staff are asked to what extent there are differences in opinion or doubts in their team regarding several statements, for example: 1) Freedom of choice for residents; 2) communication with family caregivers; and 3) accepting differences between colleagues. The instrument ranges from 1 to 5, with a higher score indicating more consensus on care philosophy.

The number of psychotropic drugs were measured using standardized registrations of prescribed benzodiazepines and anti-psychotic drugs on the day prior to the visit of the research assistant for all residents of the care home. The registrations were filled in by the old age care physicians of the care home. With the information from the registration forms, the total number of psychotropic drugs in the care home was computed and divided by the number of residents to gain an average number of prescribed drugs per resident.

In addition, the average number of physical restraints was measured by collecting data on the number of residents for whom physical restraints – for example fixation belts, chairs with table top, and extra deep chairs – were prescribed (also registered by the old age care physician). The total number of restraints was computed and divided by the number of residents. Because we studied the relationship with day-time activity involvement, the use of bed rails (night-time use) was left out of the analyses.

Family perceived involvement in care decision-making was measured within the family sample participating in the LAD-study, with the use of the Family Perception of Caregiver Role instrument[65] (FPCR). Examples of items of this instrument are 'I feel like an outsider in the care of my relative', 'It is clear that the staff have the real say about what care will be provided and how', and 'I feel like staff are there to help me provide the best possible care for my relative'. Factor analyses made it clear that eight of the original 23 items should be left out of the analyses for the internal consistency of the scale (range 1-7; Cronbach's α= .895 in our sample). The scale measures the extent to which family feels supported and involved in decisions and procedures concerning the care for their relative. A higher score on the FPCR represents more involvement in care.

4) Characteristics of job strain as perceived by care staff

Staff's job satisfaction, job characteristics from the Job-Demand-Control-Support model[66] and burnout characteristics were used as measures for staff perceptions of job strain.

The Leiden Quality of Work Questionnaire[67] (LQWQ) was used to measure job satisfaction and job characteristics. The total scale measures 11 job characteristics. For this study, the five subscales concerning the JDCS model are used: the Job Satisfaction subscale measuring job satisfaction and intention to leave (Cronbach's α=.857 in our sample), the Work and Time Pressure subscale measuring job demands (Cronbach's α= .747), the Decision Authority subscale measuring job control (Cronbach's α=.709 in our sample), the Social Support from the Supervisor subscale (Cronbach's α=.912 in our sample) and the Social Support from Co-workers subscale (Cronbach's α=.835 in our sample) measuring social support. All job characteristics were measured on a four-point scale ranging from (1) "strongly disagree" to (4) "strongly agree". Per subscale, the answers were added and means were calculated (range 1-4). A higher mean score represents a higher presence of the job characteristic.

Burnout complaints were measured with the Dutch version of the Maslach Burnout Inventory[68], the Utrecht Burnout Scale –C[69] (UBOS). The subscales of emotional exhaustion (Cronbach's α= .880 in our sample), and personal accomplishment (Cronbach's α= .777 in our sample) were used in this study. Both scales range from 0-6, where a higher score indicates more emotional exhaustion or more feelings of competence respectively.

5) Characteristics of the physical care environment

To obtain data about the size of the care home, the total number of residents of the dementia

units of the care home was registered.
As a measure for the presence of a homelike environment, the number of group-living home care characteristics were studied. Data on this indicator were obtained by the Questionnaire 'Group Living Home Characteristics'[70]. A principal axis analysis showed one factor with relatively high loadings (>0.4) of 14 items (range: 0-56; Cronbach's α = .857). Examples of items are: Living rooms have a homelike atmosphere; dinner is prepared in the kitchen of the living rooms; care staff do housekeeping; and residents can get out of bed whenever they want. The response-categories have a 5 point Lickert scale format. A higher score indicates more characteristics of group-living home care.
Since the Group Living Home Characteristics questionnaire and the average number of residents per common living room (place where residents usually stay during the day) were highly correlated (.629), the latter information was left out of the analyses.

6) Characteristics of the organization of activities
The ways in which activities were offered at the care homes were inventoried by asking the manager whether central activities were provided in fixed schedules, whether they were offered in the common living rooms of the residents, or whether activities were organized in the form of clubs, for which a particular group of residents is registered according to their personal preferences (for example the yoga or music club). The manager could choose multiple options.
We also asked whether these activity offers were provided by care staff, activity or recreational staff, volunteers or family. Again, one could choose multiple options. A dichotomous variable was made for the sole provision of activities by activity or recreational staff, and for activity provision by care staff or a combination of staff functions.
Furthermore, the number of hours per week of recreational workers or activity staff that worked for the care home were collected and divided by the number of residents at the total facility site.
Finally, data on availability of help from family caregivers and volunteers were collected. In the interview with the care manager, he or she was asked to estimate how many hours a week family caregivers and volunteers were present to actually perform care or activity tasks in the living arrangement. These numbers were divided by the number of residents in the care home.

Analysis
To study the effect of family- and staff-related predictors of activity involvement of the individual residents, the mean scores of care staff and family caregiver variables for each care home were calculated and added to the residents of the particular care home. When there were less than 4 questionnaires filled out by staff members or family caregivers of a care home respectively, the staff- or family caregiver-related predictive values of that care home were excluded from analyses, in order to minimize unrepresentative mean scores for a care home. Missing values were estimated and replaced with multiple imputation.
Multilevel analyses were performed to correct for our clustered data[71]. MLwiN 2.21 software was used as statistical computer program. The outcome variable 'time involved in activities' was highly skewed to the left. Therefore, it was dichotomized

into low involvement (3 hours in 3 days or less – in other words, 1 hour a day or less); and high involvement (more than 1 hour a day). Backward stepwise logistic regression analyses were performed to analyze which factors predicted higher activity involvement, stepwise excluding variables with the smallest and non-significant relationship to the outcome variable ($p<.05$).
Our 40 potential predicting variables were entered blockwise in the regression model: we first studied only which resident characteristics predicted high activity involvement, then which characteristics of financial resources were predictors, and so on. Ultimately, all remaining significant predictors for each block were put together in one model to perform a final backward regression analysis, in order to determine their relative impact on activity involvement.

Results

Sample

A total of 1,389 observational questionnaires on residents with dementia were filled out by care staff - a response rate of 89%. 888 family caregivers returned their questionnaires (a response rate of 52%). Complete data on activity involvement were available for 1,218 residents with dementia (88% of the returned questionnaires) representing 139 care facilities. A total of 2,160 questionnaires were distributed to staff, and 1145 care workers participated and met our criteria, resulting in a response of 53%.

Characteristics of the participants

In Table 7.3, the characteristics of the residents, staff and care homes concerning the six groups of predictors that were studied are presented. To give insight into variations in resident and care characteristics between the five Dutch care settings that were represented in this study, the later columns of Table 7.3 show the participants' characteristics across these settings.

1) Residents' characteristics

Overall, residents had a mean age of 84. The majority of the sample was female (75%) , and 25% had a life partner. Most residents resided longer than 6 months in the care home (88%). With regard to their stage of dementia, 34% of the residents had mild to moderate dementia; 24% had moderate to severe dementia, and 42% had severe to very severe dementia. The average resident had some behavioral symptoms. Agitation, depression and anxiety were present in 22% to 27% of the sample, and 45% had apathy symptoms. The average resident needed help in most domains of Activities of Daily Living. Only 15.4% needed help in less than three ADL domains. The activity involvement of the residents greatly varied. On average, residents were involved in the 17 listed activities for 152 minutes during three days. Of all residents, 32.5% were involved in activities for one hour a day or more.

2) Staff ratio and educational level

On average, the participating care homes had a staff ratio of 21 hours a week per resident, and 64% of the scheduled staff had an educational level of 3 or higher. Care homes had an average sick leave number of 6%, meaning that 6% of the originally scheduled care staff were absent from work due to sickness and had to be replaced. Care homes had around .02 vacancies per resident on average. Per week, (para)medics were involved for somewhat more than 1 hour per resident. There was considerable variation in most of these organizational characteristics however: staff ratio ranged from almost 14 to 30 hours per resident per week, and the percentage of staff with a higher educational level ranged from 23% to 100%. The average percentage of sick

leave ranged from less than 1% to 17%.

3) Traditional vs. modern care culture

Concerning care culture, facilities scored moderately high on transformational leadership, person-centered care, unity in care philosophy (scores of 3 to 4 on a scale from 1-5), and family perceived involvement in care decision-making (score of 5.5 on a scale from 1-7). On average, 0.9 psychotropic drugs per resident were prescribed, and for 10 percent of the residents, a physical restraint was used. There was a large range however concerning these latter measurements.

4) Job strain as perceived by staff

Staff that contributed to this study had a mean age of 43 years and were predominantly female. On average, they were satisfied with their work, and experienced autonomy as well as social support from colleagues and their supervisor on a regular basis (scores of 3 on the 1-4 Lickert scale). They experienced moderate levels of work demands (score of 2.45 on the scale from 1-4). Concerning burnout-complaints, they experienced some emotional exhaustion and moderate to high levels of personal competence on average (score of 1.75 and 4.73 respectively on a scale from 0-6)

5) Physical care environment

Consistent with the study design, living arrangements varied greatly in size and in terms of group-living home characteristics. The total number of residents in the dementia units of the care homes ranged from 6 to 161 residents. Traditional large-scale care homes (type 1 as presented in Table 7.3) and large-scale group living home facilities (type 3) had the highest total numbers of residents, with average numbers of 70 and 61 residents respectively. The small-scale group living home facilities (type 4 and 5), as well as the traditional dementia care units in homes for the aged, had an average resident number of 21 to 28.

In the traditional types of nursing homes (type 1 and 2), residents lived together in groups of approximately 12, whereas the group-living home care facilities (type 3, 4, 5) had 6 to 8 residents per living room.

In the 'archetypal' small scale group living home facilities (type 4), the most characteristics of group living home care were present (on average, 42 out of the maximum score of 56). The alternative group living home care facilities (type 3 and 5) had a somewhat lower score on the Group Living Home Characteristics questionnaire (34 and 37 resp.). And the traditional nursing home care facilities had the fewest characteristics of group-living home care (type 1 had an average score of 23, and type 2 of 22).

6) Organization of activities

Almost all care homes (95%) offered activities in the common living rooms, and 86% provided activities in a central activity program. In 54% of the care homes, activities were arranged in the form of clubs. In 10% of the care homes, activities were only provided by activity or recreational staff, sometimes with help of volunteers or family. In the other care homes, activities were (also) provided by care staff. Structural help from family caregivers was much lower than help from volunteers (as estimated by the care manager 0.4 and 1 hours a week on average per resident, respectively) and varied greatly between care homes.

Table 7.3: Background characteristics of participants

	Overall sample	**Type 1 CH***	**Type 2 CH***	**Type 3 CH***	**Type 4 CH***	**Type 5 CH***
Variables *(if applicable: range)*	**M (SD) or n (%)**	**M (SD) or n (%)**	**M (SD) or n (%)**	**M (SD) or n (%)**	**M (SD) or n (%)**	**M (SD) or n (%)**
1. **Resident characteristics**	**n = 1218**	**n=249**	**n=268**	**n=242**	**n=236**	**n=223**
Age *(42-101)*	M 84.10 (SD 7.42)	M 82.77 (SD 8.51)	M 85.62 (SD 6.10)	M 83.65 (SD 7.49)	M 84.19 (SD 6.41)	M 84.16 (SD 8.21)
Female residents	n 921 (% 75.7)	n 189 (% 75.9)	n 213 (% 79.5)	n 165 (% 68.2)	n 178 (% 75.4)	n 176 (% 78.9)
Residents with life partner	n 301 (% 24.7)	n 72 (% 28.9)	n 64 (% 23.9)	n 57 (% 23.6)	n 50 (% 21.2)	n 58 (% 26.0)
Residents with length of stay 6 months or more	n 1067 (% 87.6)	n 218 (% 87.5)	n 231 (% 85.8)	n 216 (% 89.2)	n 207 (% 87.7)	n 196 (% 87.9)
CPS overall score *(0-6)*	M 3.99 (SD 1.46)	M 4.11 (SD 1.46)	M 4.00 (SD 1.49)	M 4.14 (SD 1.44)	M 3.80 (SD 1.49)	M 3.87 (SD 1.40)
Residents with mild to moderate cognitive impairment *(CPS 0-3)*	n 408 (% 33.6)	n 76 (% 30.5)	n 95 (% 35.4)	n 67 (% 27.7)	n 89 (% 37.7)	n 81 (% 36.3)
Residents moderate to severe cognitive impairment *(CPS 4)*	n 297 (% 24.4)	n 61 (% 24.5)	n 55 (% 20.5)	n 57 (% 23.6)	n 62 (% 26.3)	n 27.8 (% 27.8)
Residents with severe to very severe cognitive impairment *(CPS 5-6)*	n 513 (% 42.1)	n 112 (% 45.0)	n 118 (% 44.0)	n 118 (% 48.8)	n 85 (% 36.0)	n 35.9 (% 35.9)
NPIQ *(0-36)*	M 11.52 (SD 6.31)	M 11.50 (SD 6.87)	M 11.29 (SD 6.33)	M 11.75 (SD 6.09	M 11.45 (SD 6.19)	M 11.66 (SD 6.03)
Residents with agitation symptoms	n 329 (% 27.1)	n 73 (% 29.6)	n 80 (% 29.9)	n 66 (% 27.3)	n 60 (% 25.4)	n 50 (% 22.4)
Residents with depression symptoms	n 318 (% 26.1)	n 69 (% 27.5)	n 58 (% 21.6)	n 61 (% 25.3)	n 74 (% 31.4)	n 56 (% 25.1)
Residents with anxiety symptoms	n 262 (% 21.5)	n 47 (% 19.0)	n 60 (% 22.4)	n 52 (% 21.5)	n 54 (% 22.9)	n 49 (% 22.0)
Residents with apathy symptoms	n 541 (% 44.5)	n 122 (% 49.0)	n 113 (% 42.2)	n 108 (% 44.6)	n 46.2 (% 46.2)	n 90 (% 40.4)
Katz ADL dependency *(1-7)*	M 5.35 (SD 1.65)	M 5.49 (SD 1.61)	M 5.51 (SD 1.56)	M 5.35 (SD 1.69)	M 5.20 (SD 1.71)	M 5.19 (SD 1.67)
Residents without or low ADL dependency *(Katz 1-3)*	n 181 (% 14.9)	n 32 (% 12.9)	n 32 (% 11.9)	n 40 (% 16.5)	n 18.2 (% 18.2)	n 34 (% 15.2)
Residents dependent in various ADL domains *(Katz 4-6)*	n 627 (% 51.5)	n 125 (% 50.2)	n 139 (% 51.9)	n 117 (% 48.3)	n 50.4 (% 50.4)	n 127 (% 57.0)
Residents dependent in all ADL domains *(Katz = 7)*	n 410 (% 33.7)	n 92 (% 36.9)	n 97 (% 36.2)	n 35.1 (% 35.1)	n31.4 (% 31.4)	n 62 (% 27.8)
Residents independent in transferring (with or without aids)	n 651 (% 53.6)	n 125 (% 50.2)	135 (% 50.4)	133 (% 55.0)	129 (% 54.7)	94 (% 57.8)
Minutes involved in 17 listed activities during the past three days *(0-1125)*	M 152.49 (SD 166.80)	M 120.66 (SD 150.32)	M 143.53 (SD 156.71)	M 136.08 (SD 163.07)	M 191.03 (SD 177.60)	M 175.84 (SD 178.46)
Residents ≤ 3 hour involved in activities during past three days	n 822 (% 67.5)	n 186 (% 74.7)	n 180 (% 67.3)	n 183 (% 75.6)	n 133 (% 56.4)	n 140 (% 62.8)
Residents > 3 hour involved in activities during past three days	n 396 (% 32.5)	n 63 (% 25.3)	n 88 (% 32.7)	n 59 (% 24.4)	n 103 (% 43.6)	n 83 (% 37.2)

2. **Characteristics of resources of finances, staff ratio and educational level**	**n = 139**	**n = 28**	**n = 30**	**n = 28**	**n = 28**	**n = 25**
Staff ratio *(13.86-30.48)*	M 20.86 (SD 3.61)	M 18.89 (SD 3.46)	M 20.49 (SD 3.57)	M 21.55 (SD 3.52)	M 21.59 (SD 3.24)	M 21.92 (SD 3.69)
Staff with education level 3 or higher *(22.70-100)*	M 63.55 (SD 15.58)	M 58.27 (SD 13.83)	M 63.58 (SD 13.65)	M 67.49 (SD 18.76)	M 61.85 (SD 12.69)	M 66.97 (SD 17.67)
Average % of sick leave *(0.82-17.0)*	M 6.22 (SD 3.09)	M 7.10 (SD 2.00)	M 5.12 (SD 2.60)	M 5.96 (SD 2.62)	M 6.22 (SD 3.49)	M 6.86 (SD 3.51)
Number of vacancies per resident *(0-0.22)*	M 0.016 (SD 0.034)	M 0.015 (SD 0.023)	M 0.013 (SD 0.028)	M 0.022 (SD 0.036)	M 0.022 (SD 0.052)	M 0.008 (SD 0.022)
Hours / week (para) medics per resident *(0-5.06)*	M 1.32 (SD 0.93)	M 1.70 (SD 1.11)	M 1.24 (SD 0.92)	M 1.38 (SD 0.88)	M 0.91 (SD 0.55)	M 1.38 (SD 0.99)
3. **Characteristics of modern or traditional care culture of the care facility**	**n = 139**	**n = 28**	**n = 30**	**n = 28**	**n = 28**	**n = 25**
GTL *(1.55-4.81)*	M 3.23 (SD 0.63)	M 3.13 (SD 0.67)	M 3.10 (SD 0.69)	M 3.29 (SD 0.65)	M 3.35 (SD 0.62)	M 3.30 (SD 0.54)
P-CAT *(2.76-4.35)*	M 3.62 (SD 0.34)	M 3.36 (SD 0.33)	M 3.50 (SD 0.24)	M 3.73 (SD 0.26)	M 3.87 (SD 0.31)	M 3.62 (SD 0.31)
Unanimity in care philosophy *(2.39-4.57)*	M 3.38 (SD 0.39)	M 3.19 (SD 0.33)	M 3.28 (SD 0.37)	M 3.53 (SD 0.32)	M 3.54 (SD 0.42)	M 3.35 (SD 0.37)
FPCR (*3.98-6.47)*	M 5.51 (SD 0.46)	M 5.31 (SD 0.42)	M 5.38 (SD 0.45)	M 5.50 (SD 0.44)	M 5.74 (SD 0.39)	M 5.66 (SD 0.43)
Number of psychotropic drugs per resident *(0.17-2.38)*	M 0.90 (SD 0.36)	M 1.08 (SD 0.41)	M 0.84 (SD 0.33)	M 0.92 (SD 0.29)	M 0.74 (SD 0.36)	M 0.95 (SD 0.35)
Number of physical restraints per resident *(0-0.74)*	M 0.11 (SD 0.13)	M 0.17 (SD 0.14)	M 0.12 (SD 0.18)	M 0.09 (SD 0.08)	M 0.09 (SD 0.12)	M 0.11 (SD 0.11)
4. **Characteristics of workload as perceived by care staff (mean scores per care home)**	**n = 139**	**n = 28**	**n = 30**	**n = 28**	**n = 28**	**n = 25**
LWQ Job satisfaction *(2.28-3.75)*	M 3.04 (SD 0.26)	M 2.85 (SD 0.24)	M 3.04 (SD 0.22)	M 3.09 (SD 0.25)	M 3.20 (SD 0.25)	M 3.04 (SD 0.25)
LWQ Job demands *(1.70-3.20)*	M 2.45 (SD 0.29)	M 2.70 (SD 0.25)	M 2.50 (SD 0.19)	M 2.41 (SD 0.27)	M 2.22 (SD 0.25)	M 2.41 (SD 0.27)
LWQ Autonomy *(2.33-4.00)*	M 2.95 (SD 0.21)	M 2.82 (SD 0.21)	M 2.88 (SD 0.14)	M 2.98 (SD 0.17)	M 3.11 (SD 0.16)	M 2.98 (SD 0.25)
LWQ Social support manager *(2.17-3.68)*	M 3.04 (SD 0.30)	M 2.97 (SD 0.35)	M 3.00 (SD 0.30)	M 3.06 (SD 0.34)	M 3.08 (SD 0.26)	M 3.09 (SD 0.26)
LWQ Social support coworkers *(2.40-3.88)*	M 3.21 (SD 0.23)	M 3.15 (SD 0.23)	M 3.20 (SD 0.21)	M 3.25 (SD 0.20)	M 3.22 (SD 0.28)	M 3.20 (SD 0.48)
UBOS emotional exhaustion *(0.61-3.46)*	M 1.76 (SD 0.52)	M 2.08 (SD 0.49)	M 1.82 (SD 0.57)	M 1.74 (SD 0.45)	M 1.47 (SD 0.41)	M 1.68 (SD 0.48)
UBOS Burnout personal competence (*3.71-5.79)*	M 4.73 (SD 0.31)	M 4.53 (SD 0.30)	M 4.72 (SD 0.32)	M 4.76 (SD 0.25)	M 4.84 (SD 0.29)	M 4.82 (SD 0.33)
5. **Characteristics of the physical care environment**	**n = 139**	**n = 28**	**n = 30**	**n = 28**	**n = 28**	**n = 25**
Number of residents in facility *(6-161)*	M 40.43 (SD 32.44)	M 69.54 (SD 38.68)	M 23.37 (SD 8.63)	M 60.61 (SD 34.03)	M 20.71 (SD 15.49)	M 27.80 (SD 16.14)
Number of residents per living room *(5-28)*	M 9.26 (SD 3.88)	M 12.18 (SD 2.99)	M 12.09 (SD 4.84)	M 8.07 (SD 2.91)	M 6.41 (SD 0.87)	M 7.12 (SD 1.37)

Group living home care characteristics *(9-51)*	M 31.32 (SD 10.59)	M 22.58 (SD 7.29)	M 22.47 (SD 5.74)	M 33.64 (SD 8.04)	M 42.04 (SD 5.48)	M 37.12 (SD 8.77)
6. **Characteristics of the organization of activities**	**n = 139**	**n = 28**	**n = 30**	**n = 28**	**n = 28**	**n = 25**
Care homes with activities arranged in clubs	75 (% 54.0)	n 21 (% 75.0)	n 11 (% 36.7)	n 19 (% 67.9)	n 9 (% 32.1)	n 15 (% 60.0)
Care homes with central activity program	119 (% 85.6)	n 25 (% 89.3)	n 25 (% 83.3)	n 26 (% 92.9)	n 23 (% 82.1)	n 20 (% 80.0)
Care homes with activities in living room	132 (% 95.0)	n 28 (% 100)	n 28 (% 93.3)	n 27 (% 96.4)	n 27 (% 96.4)	n 22 (% 88.0)
Care homes where activities are (also) offered by care staff	124 (% 89.2)	n 24 (% 85.7)	n 26 (% 86.7)	n 27 (% 96.4)	n 24 (% 85.7)	n 23 (% 92.0)
Hours / week recreational staff per resident *(0-4.71)*	M 0.78 (SD 0.78)	M 1.12 (SD 0.85)	M 1.17 (SD 0.92)	M 0.75 (SD 0.50	M 0.12 (SD 0.19)	M 0.74 (SD 0.69)
Hours of help from family caregivers per resident per week *(0-4.20)*	M 0.36 (SD 0.68)	M 0.24 (SD 0.53)	M 0.16 (SD 0.28)	M 0.33 (SD 0.67	M 0.66 (SD 0.81)	M 0.39 (SD 0.90)
Hours of help from volunteers per resident per week *(0-6.67)*	M 1.06 (SD 1.08)	M 0.62 (SD 0.78)	M 0.89 (SD 0.57)	M 1.21 (SD 1.25	M 1.58 (SD 1.46)	M 0.95 (SD 0.93)

* Types of care homes that were represented in the LAD-study: 1) traditional large scale nursing homes; 2) nursing home units in homes for the aged; 3) large scale group living homes (>36 residents with dementia); 4) small scale group living homes (< 36 residents) only providing group living home care, 5) small scale group living homes with other care forms at same location.

Results of blockwise analyses of predictors of activity involvement

Table 7.4 shows the results of the blockwise prediction analyses.

1) Resident characteristics

The prediction model of resident characteristics was filled with the variables age, gender, having a life partner, length of stay, ADL dependency, immobility, cognitive impairment, overall behavioral symptoms, and depression, agitation, anxiety, and apathy. Backward regression analysis revealed that out of these variables only agitated behavior (Odds Ratio .489), ADL dependency (OR .809) and cognitive impairment (OR .746) were predictors of activity involvement. As shown by the Odds Ratios, these characteristics were all negatively related to higher activity involvement.

2) Resources of finances, staff ratio and educational level

Concerning the financial resources of the care homes, staffing levels, staff educational level, availability of (para)medics, the number of vacancies and sick leave were entered in the model. It was found that a higher staff ratio (OR 1.492) and a higher percentage of staff with educational level three or higher (OR 1.009) predicted higher activity involvement of residents.

3) Traditional vs. modern care culture

Out of the variables representing care culture - transformational leadership, person-centered care, family perceived involvement, unity in the philosophy of care, psychotropic drug prescription and physical restraint use - three variables had a predictive value. Higher scores for family perceived involvement (OR 1.37) and more unity in care philosophy (OR 1.623), predicted higher activity involvement; whereas more transformational leadership predicted lower activity involvement by residents (OR .751).

4) Job strain as perceived by staff

Our analysis of the variables that represented job strain factors commenced with the variables job

demands, decision authority, burn-out complaints, job satisfaction, social support from the supervisor, social support of colleagues, and feelings of competence. The results show that higher job demands (OR .333) were related to lower activity involvement, as was more perceived social support from the supervisor (OR .457).

5) Physical care environment

With regard to characteristics of the physical environment, the number of residents in the dementia care units, and group living home characteristics were entered as variables. Both factors predicted activity involvement: more residents in the dementia care units (OR .992) was related to less activity involvement, whereas more group living home characteristics predicted higher activity involvement (OR 1.015).

6) Organization of activities

When looking at the way in which activities are organized in care homes with the variables of a central activity program, activities organized in clubs, activities offered in the living room, activities also organized by care staff, availability of recreational staff, and hours of informal help, two variables are found to have a predictive value. More help of volunteers (OR 1.14) predicted higher activity involvement, while an activity offer organized in activity clubs was related to lower activity involvement (OR .755).

Table 7.4: Results of blockwise backward prediction analyses

	Higher activity involvement		
	B	*SE*	*OR*
Block 1: characteristics of residents with dementia			
Agitation	-.715***	.161	.489
Katz	-.212***	.047	.809
CPS	-.293***	.055	.746
Block 2: characteristics of resources of finances, staff ratio and educational level			
Staff ratio	.040*	.017	1.492
Education level	.009*	.004	1.009
Block 3: characteristics of modern or traditional care culture			
GTL	-.286*	.104	.751
FPCR	.315*	.141	1.370
Unity in Care Philosophy questionnaire	.484*	.170	1.623
Block 4: characteristics of job strain as perceived by staff			
LQWQ Working demands	-1.100***	.247	.333
LQWQ Social support supervisor	-.784***	.232	.457
Block 5: characteristics of physical care environment			
Total # of residents	-.008***	.002	.992
Group living home characteristics	.015*	.006	1.015
Block 6: characteristics of organization of activities			
Activities in clubs	-.281*	.123	.755
Help of volunteers	.125*	.056	1.142

* p<0.05. ** p < 0.01, *** p < 0.001

Note: CPS, cognitive performance scale; NPI-Q, 12 item Neuropsychiatric Inventory questionnaire; KATZ, ADL dependency; LQWQ, Leiden Quality of Work Questionnaire; Staff ratio in hours of care staff per resident per week; GTL, transformational leadership; P-CAT, person-centered care; Group living home characteristics, short version of the Questionnaire 'Group Living Home Characteristics.

Results of the end model of predictors of activity involvement

In Table 7.5, the end model is presented after putting all significant predictors of the different blocks in one prediction model (agitation, ADL dependency, cognitive impairment, staff ratio, education level, transformational leadership, family perceived involvement, unity in care philosophy, job demands, social support supervisor, total number of residents in dementia units, group living home characteristics, activities organized in clubs, and availability of help from volunteers). Out of the initial 40 factors that were studied, seven variables were found to be significant predictors in the end model, and thus played a key role in the activity involvement of residents with dementia. Agitated behavior (OR .490), more ADL dependency (OR .805) and more cognitive impairment (OR .733) were negatively related to activity involvement. A higher staff educational level (OR 1.012) predicted higher activity involvement, whereas more perceived job demands among staff (OR .435) and higher levels of perceived supervisor support (OR .458) negatively influenced activity involvement. Furthermore, a higher total number of residents in the dementia care units (OR .994) was related to less activity involvement.

Table 7.5: End results when all predictive factors of blockwise analyses are put together in 1 model

	Higher activity involvement		
	B	*SE*	*OR*
Agitation	-.713***	0.163	.490
Katz	-.217***	0.048	.805
CPS	-.293***	.056	.746
Education level staff	.012**	.004	1.012
LWQ Working demands	-.833**	.271	.435
LWQ Social supervisor support	-.822**	.251	.440
Number of residents at facility site	-.006**	.002	.994

* p<0.05. ** p < 0.01, *** p < 0.001

Notes: CPS, cognitive performance scale; NPI-Q, 12 item Neuropsychiatric Inventory questionnaire; KATZ, ADL dependency; LQWQ, Leiden Quality of Work Questionnaire.

Discussion

In this study, a wide range of variables that were previously found or thought to impact the activity involvement of long-term-care home residents with dementia were studied. We found that several factors significantly predicted higher activity involvement - defined as involvement in activities for more than one hour a day. These factors were a higher staff ratio and higher staff educational level, more involvement of family caregivers in the decisions and procedures in the care for their relative, greater unity in the care philosophy of staff, more group living home care characteristics, and more help from volunteers at the care home. Agitated behavior, cognitive impairment and ADL dependency were negatively associated with higher activity involvement, as was transformational leadership, more perceived job demands and more supervisor support, more residents in the care home and offering activities in the form of clubs. Of these predictors, the presence of agitated behavior in residents, physical and cognitive functional level, more staff with educational level 3 or higher, more perceived job demands and social supervisor support, and the total number of residents in the care home were found to have the most important impact on activity involvement.

The finding that more cognitively and physically impaired residents are less involved in activities is consistent with the literature[9,15,16,17,19,20,22,24,26]. Although activity involvement remains important for people with more cognitive and physical limitations[14], it seems difficult for staff to reach high levels of occupation among these residents.

This might be explained by the time pressure on care staff ensuing from complex care demands. Presumably, more physically and cognitively impaired residents need more time-consuming physical care, leaving care staff with less time to offer activities and forcing them to mainly focus on care instead of recreational tasks. If this is true, care staff must learn to integrate physical care with meaningful occupation when residents' care demands increase, in order to address higher activity and wellbeing levels amongst more impaired residents. Examples include singing, playing someone's favorite music, or giving a massage while bathing. It is about making contact, and taking time to do so[72].

On the other hand, the negative relationship between more cognitive and physical impairment and activity involvement can be caused by limited knowledge among staff on how to offer appropriate activities to this resident group. Engaging severely impaired residents in activities requires special skills and the use of adjusted materials, based on the (limited) capabilities that are preserved[73]. With the increasing care dependency of residents in long-term-care homes, it is important to train care staff in assessing the capabilities and interests of residents and developing the required activity skills[48,72,73], also for the involvement of more care-dependent residents.

The same holds for our study finding that residents with agitated behavior are less likely to be involved in activities. If activities are tailored to the specific level of function, residents with this behavior might still be able to be engaged[18].

Educating staff in the provision of suitable activities and the integration in the daily care thus seems a key factor for increasing activity involvement of residents with dementia. In the Netherlands, some care homes are working already with 'recreational coaches': former recreational staff that are tasked with developing individual activity plans for residents, and teaching regular care staff (with a nursing education) to integrate the provision of activities into their daily work. Although individual activity plans may suit residents better than the traditional organization of activities[4], the recreational coach is also often the result of a financial reorganization, whereby the team of recreational workers that were responsible for all activity involvement of residents, is limited to one or two staff members that are labeled as 'recreational coaches'. The level of knowledge of the therapeutic value of activities for residents (e.g. gaining self-esteem, social contact, activation, stimulation of the senses or memory, emotional expression), and of the available materials and activity types (e.g. reminiscence activities, sports and exercise materials for older people, material for sensory stimulation) is often low, as is sometimes the willingness among care staff to perform activities. This reorganization of activity provision therefore seems to have had a negative instead of positive effect on activity involvement among residents. The limited attention to activities by care homes and the need for the development of skills amongst care staff has recently been recognized by the Dutch government. Care homes receive substantial fees when they measurably stimulate activity provision amongst their care staff, during the period from 2016-2020[74]. Hopefully, this will lead to the development of sustainable knowledge and skills among care staff on this topic. This movement can be strengthened by including activity provision in the training for RNs or CNAs.

Although offering activities to residents that are adjusted to their competences and interests is important[72], the development in care homes to organize activities in clubs for fixed small groups of residents based on their interests and life history,

did not prove to be beneficial in this study. This finding might be explained by a deprivation of activity involvement in daily life outside the club offer, which is often only provided once a week. Although certain types of activities are known to particularly influence wellbeing[46,49], it seems that frequent activity involvement is more important than involvement in a specific activity sporadically[75]. It may be also be the case that residents who do not thrive in group activities are overlooked with a club-wise activity arrangement.

Concerning the environment, a smaller number of residents at the total facility site was shown to be an important predictor of activity involvement of residents, as was also found in previous research[44]. Consistent with the literature, group living home care characteristics were likewise found to be positively related to higher activity involvement of residents with dementia. Ideally, in group living care facilities, small teams of staff provide care to a small group of residents, enabling staff to get to know residents better[76]. The homelike environment that invites residents to participate in household chores and normal life is assumed to result in higher activity involvement[44,77]. Although the concept of group-living home care was introduced years ago (the first Dutch small-scale group living home facility dates back to 1989), and its principles are widely recognized as good dementia care practice[77], some care facilities still struggle to capture the essence of the concept and to put the accompanying working style into practice. For example, there are modern group living home care facilities in the Netherlands with large kitchens in each living area to cook with or for residents, but where the value of cooking meals is not recognized and the kitchens are not used[78]. However, the extent to which group-living home care is provided, was found to be subordinate to the number of residents at the total facility site, when both factors were added to the end model of predictors. This is an important finding, since many care facilities try to offer group living home care to larger clusters of resident groups. Providing small-scale care within a large- scale setting, might not be a good alternative for the archetypal[76] small-scale group living home care in terms of residents' occupation. Perhaps, providing care on a large scale hampers the care home in providing truly individually tailored care, based on personal contact with residents and family caregivers. We did find that the level of involvement of relatives in decision-making about the care that is delivered, and better communication with relatives and staff, also predicted higher activity involvement, although this factor was of secondary importance.

This might be explained by the finding that meaningful occupation is seen as an important aspect of quality of care by family caregivers[5,6], and that their involvement leads to better advocacy of the provision of activities to their relative with dementia. Or that family involvement leads to more interaction and enthusiasm in staff to involve the person with dementia in activities.

Furthermore, a care philosophy that is clear among the care staff, for example on communication with family caregivers, also plays a role in higher activity involvement. In previous research, a clear care philosophy for staff, management as well as family, was found to be the key factor in providing good care for living arrangements for people with dementia because it served as a true guide for how to deliver care, and it provided answers in difficult situations[79].

Inconsistently with the literature, the supervisor support perceived by care staff was found to be negatively related to higher activity involvement. Based on the assumption that care staff would find themselves more supported in the choices they make, for example in spending time on interacting with residents, we did not expect to find a negative association. The same holds for transformational leadership, since it stands for being a role model, being supportive, giving room for the own creativity and ideas of staff, and being visionary[80]. If a supervisor is not activity-minded however, supportive leadership might result in less activation than directive leadership by someone who strongly values activity provision to residents. More research is needed to explore this relationship.

In our study we found that higher job demands as perceived by care staff strongly predicted residents' lower activity involvement. Several interventions to reduce job demands and job strain are proposed. These include giving staff more influence in making their own work schedules[81], giving them more decision-making authority[82], reviewing time-consuming rules and regulations which care staff have to act upon (the Dutch government is currently working on this[81]), or replacing working routines with the provision of person-centered care[83]. However, it is likely that job demands were at least partly caused by staffing levels, since these factors were correlated in this study.

Both higher staff ratio (subordinate) and higher staff educational level predicted greater activity involvement among residents. These factors are based on the financial resources of care facilities and are often perceived as hard to influence in times of economic recession. However, the care homes in our study varied greatly in educational level and staff ratio (ranging from 23 to 100% of staff with educational level 3 or higher, and 13.86 to 30.48 hours of care staff a week per resident respectively) while having more or less the same financial input per resident. Staff ratio and educational level were not correlated in the analyses. In other words, a higher staffing level was not explained by a higher percentage of staff with a lower educational level. This insight highlights the urgent need for care homes to look into the distribution of their financial means. A less hierarchical organization of the larger care providers and a review of overhead costs (for example, losing the secretary, policy makers or the laundry service), might be a key factor in better spending the available means.

Attracting volunteers can be another solution to increase the number of people who are willing to engage residents in activities. In this study, we found that more hours of help from volunteers related to higher activity involvement among residents. Earlier, we found that there is much variety in the number and quality of volunteers available in care homes[79]. Several care homes have reported that they experience difficulty in finding and retaining volunteers. Care homes with many volunteers report that it requires creativity and reciprocity to attract and keep volunteers. A culture change is needed: from care homes where volunteers are perceived as visitors who solely contribute to the organization, to a place where they are truly part of the organization, where they feel welcome and where they contribute but also gain from their work, such as receiving learning possibilities, experience being part of a team, or receive support in a job-finding process. Care homes may be helped by sharing experiences. This requires the willingness to do so, which is not always the case when policy is focused on market mechanisms, giving care homes the idea that they need to compete.

To summarize, a change towards better education on activity provision and more archetypal small- scale group living home care provision, with a clear wellbeing-focused philosophy of care among staff and management and good cooperation with family in care provision for a resident, might result in higher activity involvement. However, appropriate conditions for good care provision need to be created first.

This study has strengths and limitations. Strong features are the large numbers of participants, representing a large number of dementia care homes in the Netherlands, and the wide variety of factors included in this study. A limitation is that, although causality is an underlying assumption in backward prediction analyses, this study gives no causal certainty over the relationships found due to

the cross-sectional character of our study.

Furthermore, we were not able to study all factors that were found or proposed in literature to influence activity involvement, since not all factors were measured in the LAD-study. Therefore, some important predictors might have been missed, for example the role of specific environmental features (e.g. access to a garden[34] or light intensity in the living arrangement[23,47]). For most factors that were studied, there was a clear measurement instrument available in the LAD-study. However, sometimes, an instrument was used that approached a factor mentioned in literature (e.g. for the factor 'instability in care teams' we used the number of vacancies per resident, and for *'knowledge about dementia / lack of skills / formal staff training',* we used the percentage of staff with a higher education level).

For feasibility reasons, we were not able to train staff in completing the observational questionnaires on resident characteristics and outcomes. This may have influenced the data, since instruments were used that might have needed further explanation. To illustrate, about 1 percent of our study sample had a Cognitive Performance Scale (CPS) sore of 0, indicating that these persons had no signs of cognitive problems. Since all residents participating in this study lived in dementia care units based on a diagnosis of dementia or other cognitive problems, a score of 0 is questionable. On occasion, a person might have scored low on the CPS due to an alternative form of dementia without clear signs of memory impairment in the earlier stages of the disease (for example frontal lobe dementia). But when talking with staff about their scorings of, for example, the CPS, we found that some of them overestimated the cognitive performances of residents based on their own support. For example, they scored a resident who suffered from severe aphasia as 'having no problems in making himself clear', because they normally could understand the person without using many words. Based on this experience, we strongly recommend clear instructions for care staff on filling in the CPS before use.

Moreover, the reliability and validity of the instrument used for measuring time of activity involvement is unclear. To our knowledge, little specific information is available on the intra- and interrater reliability of the standardized Activity Pursuit Patterns of the MDS[56,57]. It is mentioned however that the instrument was filled in with little accuracy[84]. Our experience with the instrument confirms this. The instrument relies on the observations of care staff regarding activity involvement by residents during the past three days. It is doubtful that observations could be recorded entirely by the staff member filling in the questionnaire, all the more so because in this study, the Activity Pursuit Patterns was expanded with a time variable. Care staff work in shifts, making them dependent on reports and observations of colleagues. This probably resulted in estimations of time involved in activities instead of real-time involvement. Also, the fact that residents were reported to be involved in certain types of activities for extreme lengths of time, makes it likely that some staff found it difficult to discriminate actual activity involvement from being present in a room with stimuli. This could have resulted in an overestimation of activity involvement. For this reason, the activities talking, watching television and listening to music or radio, were excluded from the analyses, with consequences for the reliability of the data. Unfortunately, at the time of data collection, no good alternative instrument was available in terms of psychometric properties and feasibility. Ideally, activity involvement is measured by real-time observational instruments such as Dementia Care Mapping[13]. However, Dementia Care Mapping is time-consuming, and it requires certified 'mappers' to collect the data. Furthermore, occupation of residents is only measured when they are in the common living room of their care unit, thereby eliminating the activities that are done outside this common space, for example in recreational areas or the private room of the person with dementia. Just recently, the Maastricht Electronical Daily Life Observation (MEDLO) method was developed[85]. With MEDLO, occupation in daily life of residents with dementia throughout the care home is observed using tablets,

making it more easy to report on. However, a convenient sample of residents available at that time is observed and trained observers still have to be present at the location sites. For a large-scale study such as the LAD-study, staff observations of actual activity involvement are preferable. Staff have to be trained properly though, mainly in differentiating actual involvement in activities from being present in a room where activities are available.

Conclusions

The lack of activity involvement by care home residents with dementia may be targeted with programs focusing on: 1) Reducing the working demands that are experienced by care staff; 2) Increasing staff's educational level and staffing levels; 3) Training staff in providing suitable and accessible activities concerning the behavior, cognitive capacity and functional ability of residents and the integration of activities in daily care; and 4) Limiting resident numbers at a facility site and securing the proper implementation of the essence of the group living home care environment; furthermore, 5) Working by a clear philosophy on care that focuses on the wellbeing of residents and the involvement of family caregivers, and 6) Attracting and retaining volunteers might help increase activity involvement amongst residents with dementia.

To act upon these directions, the redistribution of the available means within care homes might be essential. Therefore, the key factor in turning around passiveness may still be recognizing the value of activities for residents with dementia, both by care staff, care home directors and policy makers.

List of abbreviations

None.

Declarations

Ethical approval and consent to participate

For this study, the usual daily practice in nursing home care for people with dementia was studied without disturbing the residents in any way. Data of residents were collected through observational questionnaires by the regular care staff and processed anonymously. The Dutch medical-ethics committee METiGG declared that this study did not come within the scope of the Medical Research Involving Human Subjects Act (WMO) and therefore needed no approval.

Regarding the questionnaires filled in by care staff, staff received written information on the purpose and use of the study data. They were not asked to fill in informed consent forms since they were free to not return the questionnaire if they did not wish to participate and the questionnaires were fully anonymous.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Availability of data and materials

Data collected and used for this study can be made available upon reasonable

request for validation purposes or non-commercial research, when permitted by the participating living arrangements.

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Authors' contributions
DS, JdL and AMP developed the research questions as described in this paper. DS did the literature review, analyzed the data and drafted the manuscript. BW helped in analyzing the data, and helped to draft the manuscript as did JdL. AMP helped to draft the manuscript, checked the analyses, and was principal investigator of the LAD-study. All authors contributed to the design of the LAD-study. All authors read and approved the final paper for publication.

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Appendix - Chapter 7

Appendix 1: overview of enabling and disabling factors of activity involvement of residents in long term dementia care as studied or suggested in literature (using search string '[dementia OR alzheimer's] AND [long term care OR nursing home OR elderly care OR homes for the aged] AND [activity OR occupation OR leisure OR meaningful activities OR engagement OR involvement OR wellbeing OR quality of life]' in pubmed, web of science and psychinfo, following snowball method)

Authors / year	Study description	Type of study	# study subjects	Factor(s)	Enabling / disabling	Suggested / studied in quantitative research / study result from qualitative research
Abrahamson *et al.*, 2012[19]	Study on the influence of cognitive impairment and facility characteristics on quality of life	Cross sectional study	13983	RESIDENTS Cognitive impairment PHYSICAL ENVIRONMENT Special care unit	 Disabling Enabling	 Studied, confirmed Studied, confirmed
Bates-Jensen, Schnelle et al., 2004[30]	To study the effect of low staffing levels on daytime sleep, social engagement and food and fluid intake	Cross sectional study	882	STAFF RATIO Low staffing level	 Disabling	 Studied, confirmed
Van Beek *et al.*, 2010[26]	Study on explanatory role of residents' characteristics and differences in care setting on social engagement including individual activities	Cross sectional study	502	RESIDENTS Higher age More social resources Problems in ADL Problems in cognitive performance	 Disabling Enabling Disabling Disabling	 Studied, n.s. Suggested Studied, confirmed Studied, confirmed
Buettner, 1999[29]	Study on the effects of handmade recreational items on behavior of residents and impact on family visits, staff knowledge and volunteer involvement	Experimental study with cross over design	55	STAFF RATIO Shortness of time and resources ACTIVITY OFFER Good supply and ready access to sensimotor recreational items	 Disabling Enabling	 Suggested Studied, confirmed
Buettner and Fitzsimmons, 2003[20]	Study on activity calendar offerings, leisure, preference and actual involvement	Case control study	107	RESIDENTS Higher cognitive impairment Higher ADL dependency CARE CULTURE Psychotropic drug use ACTIVITY OFFER Use of standard activity schedules instead of individualized activities	 Disabling Disabling Disabling Disabling	 Studied, confirmed Studied, confirmed Studied, confirmed Studied, confirmed

Brooker and Woolley, 2007; Brooker, Woolley and Lee, 2007[4]	Study on the effect of the Enriched opportunities program (sustainable multi-level activity based model of care)	Repeated measures within subjects design	115	STAFF RATIO Instability of staff CARE CULTURE Person-centered care Strong management and leadership PHYSICAL ENVIRONMENT Communal space and equipment Getting out of the facility Individual assessment of abilities, life history, personality and interests Individualized simple and fun activity and occupation Staff training Senior staff role ensuring residents reach potential wellbeing	 Disabling Enabling Enabling Enabling Enabling Enabling Enabling Enabling Enabling	 Suggested Studied, *confirmed** Studied, *confirmed** Studied, *confirmed** Studied, *confirmed** Studied, *confirmed** Studied, *confirmed** Studied, *confirmed** Studied, *confirmed**
Cohen-Mansfield et al., 2009 [24]	Study on impact personal characteristics on engagement	cross sectional study	193	RESIDENTS Female gender Higher comorbidity Index Higher ADL dependence Higher cognitive functioning Speech clarity Making self understood Poor hearing CARE CULTURE Higher number of medications ACTIVITY OFFER More activities of past interest to participant	 Enabling Disabling Disabling Disabling Enabling Enabling Disabling Disabling Enabling	 Studied, trend Studied, confirmed Studied, confirmed Studied, confirmed Studied, confirmed Studied, confirmed Studied, n.s. Studied, n.s. Studied, confirmed
Cohen-Mansfield *et al.,* 2010 [46]	Study to determine which stimuli are engaging, refused and appropriate	Experimental study	193	ACTIVITY OFFER Adjustment of type of stimuli to gender, cognitive function Real stimuli, representative of real world tasks, social stimuli and task oriented activities	 Enabling Enabling	 Studied, confirmed Studied, confirmed

* these factors are components of the Enriching opportunities program. The program as a whole had positive effects on activity involvement. However, the different components of the intervention were not studied separately so it is uncertain whether or not all these components indeed contribute to higher activity involvement.

Cohen-Mansfield *et al.*, 2010 [47]	Study on impact of setting characteristics and presentation effects on engagement with stimuli	Intervention study	193	PHYSICAL ENVIRONMENT		
				Normal or bright light (not dark)	Enabling	Studied, confirmed
				Moderate levels of sound	Enabling	Studied, confirmed
				Presence of small group of people (4-9)	Enabling	Studied, confirmed
				ACTIVITY OFFER		
				Modeling of appropriate behavior	Enabling	Studied, confirmed
				Activities in the afternoon instead of morning	Enabling	Studied, confirmed
Dobbs *et al.*, 2005 [17]	Study on characteristics associated with lower activity involvement	cross sectional study	421	RESIDENTS		
				Depression	Disabling	Studied, n.s.
				Behavioral symptoms	Disabling	Studied, n.s.
				Pain	Disabling	Studied, n.s.
				Immobility	Disabling	Studied, n.s.
				ADL dependency	Disabling	Studied, confirmed
				Low food intake	Disabling	Studied, n.s.
				Cognition	Disabling	Studied, confirmed
				STAFF PERCEPTIONS		
				Feeling of competence to provide suited activities	Enabling	Studied, n.s.
				PHYSICAL ENVIRONMENT		
				For profit organization	Enabling	Studied, n.s.
				Smaller size	Enabling	Studied, n.s.
				CARE CULTURE		
				Family involved in assessment activities	Enabling	Studied, confirmed
				Staff assessment of activity abilities and preferences	Enabling	Studied, n.s.
				ACTIVITY OFFER		
				Family involvement (hr/week)	Enabling	Studied, confirmed
				Higher activity provision level	Enabling	Studied, n.s.
				Staff encouragement of activity in volvement	Enabling	Studied, confirmed
				Training to facilitate activity provision	Enabling	Studied, n.s.

Ducak, Denton and Elliot, 2016 [28]	Study on factors that affected implementation of Montessori Methods for Dementia in Canadian long term care homes	Qualitative study using semi structured telephone interviews	17 recreation staff and multidisciplinary consultants'	STAFF PERCEPTIONS Support of manager and colleagues STAFF RATIO Limited resources CARE CULTURE Task oriented work environment Limited knowledge on beneficial effects of activities of staff ACTIVITY OFFER Activities provided by recreational staff OTHER Restrictive rules and regulations of government	 Enabling Disabling Disabling Disabling Disabling Disabling	 Study result Study result Study result Study result Study result Study result
Edvardsson, 2013 [37]	Study on the relationship between percent centered care, quality of life and participation in everyday activities	cross sectional study	1266	RESIDENTS Higher cognitive scores STAFF PERCEPTIONS Perceived high workload CARE CULTURE Person centered care Task oriented working / inflexibility Biographical and functional knowl edge of residents	 Enabling Disabling Enabling Disabling Enabling	 Studied, confirmed Suggested Studied, confirmed Suggested Suggested
Fleming and Purandare, 2010 [41]	Study to identify which environmental recommendations should be used in the design of long term care facilities for persons with dementia	Literature review	148 relevant articles	PHYSICAL ENVIRONMENT Homelikeness and presence of outside space, when combined with staff interaction / encouragement	 Enabling	 Studied, confirmed

Green and Cooper, 2000 [36]	Study on factors that contribute most to occupational performance in nursing homes (not dementia specific)	Qualitative study using semi- structured interviews	20 care managers	RESIDENTS Residents ability and level of motivation CARE CULTURE Strong leadership Philosophy of care Organizational routines limiting autonomy of residents ACTIVITY OFFER Residents control over and choice of activity Recognition of value of 'normal activities'	 Enabling Enabling Enabling Disabling Enabling Enabling	 Study result Study result Study result Study result Study result Study result
Hancock *et al.*, 2006 [9]	Study to identify unmet needs or people with dementia and characteristics associated with high levels of unmet needs. Study outcome is score on CANE scale of unmet needs, with stimulating daytime activities as most commonly scored unmet need.	cross sectional study	238	RESIDENTS Behavioral problems Younger age Shorter length of stay Depression Anxiety	 Disabling Disabling Disabling Disabling Disabling	 Studied, confirmed Studied, confirmed Studied, confirmed Studied, confirmed Studied, confirmed

Harmer and Orrell, 2008 [27]	Study on concept of meaningful activity as defined by people with dementia in care homes, staff and family caregivers	Qualitative study using focus group interviews	17 residents 15 staff 8 family	RESIDENTS Loss of abilities due to cognitive impairment Communication problems in ethnic minority groups Lack of motivation / loss of interest STAFF RATIO Lack of skills Lack of sufficient staff CARE CULTURE Prioritization of physical over psychosocial needs Lack of knowledge on importance of engagement in activities ACTIVITY OFFER Suited activity offer adjusted to skills and preference Lack of organized activities Activity provision not restricted to activity workers	 Disabling Disabling Disabling Disabling Disabling Disabling Disabling Enabling Disabling Enabling	 Study result Study result Study result Study result Study result Study result Study result Study result Study result Study result
Kolanowski *et al.*, 2006 [18]	Study on predictors of time of engagement and participation in activities matched to skill level, activities that matched interests, and both	Cross over experimental	30	RESIDENTS Agitation Passivity Higher MMSE score ADL dependency CARE CULTURE (Psychotropic) medication use	 Disabling Disabling Enabling Disabling Disabling	 Studied, n.s. Studied, n.s. Studied, confirmed Studied, confirmed Studied, n.s.
Kolanowski et al., 2009 [32]	Study on the anticholinergic burden of nursing home residents with dementia and the association between use of anticholinergic drugs and activity engagement.	Cross sectional study	116	RESIDENTS Non-treated depression STAFF RATIO Low staff ratio CARE CULTURE Anticholinergic drug use ACTIVITY OFFER Poor quality of activity offer	 Disabling Disabling Disabling Disabling	 Suggested Suggested Studied, n.s. Suggested

Kolanowski, 2011 [48]	Study on effect of theory based activity intervention on behavioral symptoms	Randomized controlled trial	128	ACTIVITY OFFER Activities adjusted on skill level and personal interests	Enabling	Studied, confirmed
Kolanowski *et al.*, 2012 [25]	Study on the relationship between mood and personality factors and attention, time on task and disengagement in an activity intervention	Randomized controlled trial	128	RESIDENTS Positive self-rated mood Neuroticism conscientiousness	Enabling Disabling Enabling	Studied, confirmed Studied, n.s. Studied, n.s.
Kuhn, Fulton & Edelman, 2004 [15]	Study on the influence on cognitive and functional impairment and care setting on participation in activities	Dementia care mapping observations	166	RESIDENTS Cognitive impairment Functional impairment STAFF PERCEPTIONS Lack of skills CARE CULTURE Psychotropic drug use ACTIVITY OFFER Large group activities	Disabling Disabling Disabling Disabling	Studied, *confirmed* Studied, *confirmed* Suggested Suggested
LeBlanc *et al.*, 2006 [49]	Study on the effect of 4 versions of a 2-choice preference assessment on engagement	Case control study	4	ACTIVITY OFFER Offering activity choices	Enabling	Study result
Morgan-Brown, Newton and Ormerod, 2013 [45]	Study on social engagement and interactive occupation before and after conversion of nursing homes to a household model environment	Observational study using snapshot observation method		PHYSICAL ENVIRONMENT Household environment	Enabling	Studied, confirmed
Nolan, Grant and Nolan, 1995 [50]	Study on interaction and activity levels amongst respite, long stay and short stay patients in two hospital settings and beliefs of care staff.	Mixed methods of naturalistic field observation and staff questionnaires	49 residents 24 staff	ACTIVITY OFFER Activity workers solely provide activities Activity provision is not seen as part of role care staff	Disabling Disabling	Study result Study result

den Ouden et al., 2015 [12]	Study to provide insight into the daily activities of psychogeriatric and somatic nursing home residents and body positions during these activities	Cross-sectional observation study	723	STAFF PERCEPTIONS High workload Negative work experience STAFF RATIO Amount of staff Education level CARE CULTURE Negative attitude toward activities ACTIVITY OFFER Lack of relevant and meaningful activities PHYSICAL ENVIRONMENT Occupation stimulating environment	 Disabling Disabling Enabling Enabling Disabling Disabling Enabling	 Suggested Suggested Suggested Suggested Suggested Suggested Suggested
Orsulic-Jenas, Judge and Camp, 2000 [83]	Study on the effect of Montessori-based activities on engagement and affect	Experimental case-control	16	ACTIVITY OFFER Large group activity offer Individual and small group activity offer	 Disabling Enabling	 Suggested Study result
Perrin, 1997 [34]	Study to identify occupational need in severe dementia	Dementia care mapping observations	109	STAFF RATIO Lack of skills Insufficient knowledge of dementia CARE CULTURE Focus on task related work	 Disabling Disabling Disabling	 Suggestion Suggestion Suggestion
Pulsford, 1997 [33]	Study on which therapeutic activities are provided, their effectiveness, and reasons why they are sometimes not offered	Literature review	No information available	STAFF PERCEPTIONS Emotional and task related demands lack of time lack of skills STAFF RATIO Shortness of staff CARE CULTURE 'not my job' No perceived benefit from activities Person centered care (looking at the benefits for the individual, no 'all or nothing thinking')	 Disabling Disabling Disabling Disabling Disabling Disabling Enabling	 Study result Study result Study result Study result Study result Study result Study result

Schwarz, Chaudhury and Tofle, 2004 [42]	Study on the effects of design interventions in long term care facility on resident and staff perceptions of care delivery	Pretest protest behavioral mapping around altering environment, focus groups	3 mapping periods on 20-30 residents	STAFF RATIO High staff turnover PHYSICAL ENVIRONMENT Homelike environment Gap between environment and corresponding activities ACTIVITY OFFER Staff straining in provision of small group activities	 Disabling Enabling Disabling Enabling	 Suggested Study result Study result Study result
Smit *et al.*, 2012 [44]	Study on the relationship between small scale care and activity involvement	Cross sectional study	1327	PHYSICAL ENVIRONMENT Small scale group home living care characteristics Smaller number of residents in facility	 Enabling Disabling	 Studied, confirmed Studied, n.s.
Smit *et al.*, 2013 [51]	Study on offered types of occupation and organizational and environmental contributing study	Explorative observational study using Dementia care mapping	57	PHYSICAL ENVIRONMENT Homelike atmosphere Social interaction enhancing environment ACTIVITY OFFER Absence of central activity program	 Enabling Enabling Enabling	 Study result Study result Study result
Tak et al., 2015 [23]	Study on types of activity involvement and barriers to activities as perceived by nursing home residents with dementia.	Qualitative study with short open ended interviews and in depth interviews	37	RESIDENTS Physical limitations (e.g. back problems, hearing, eye sight) PHYSICAL ENVIRONMENT Accurate light and sound levels ACTIVITY OFFER Availability of various, sufficient and ongoing activities Resources for activities (space, transportation, materials) Meaningful activities tailored to needs, preferences and capacities Involving residents in planning of activities Up to date activity plans for each resident	 Disabling Enabling Enabling Enabling Enabling Enabling	 Study result Study result Study result Study result Study result Study result

Train *et al.*, 2005 [35]	Study to explore positive and negative experiences of family carers, staff and people with dementia in long term care settings	Qualitative study with semi structured interviews	21 residents, 17 relatives, 30 staff	STAFF PERCEPTIONS Work load – lack of time STAFF RATIO Leave of skilled staff that were not replaced ACTIVITY OFFER Tailored activities to individual needs instead of group activities	 Disabling Disabling Enabling	 Study result Study result Study result
Verbeek *et al.*, 2010 [43]	Study on the effects of small scale living dementia care facilities on residents, family caregivers and staff	Quasi experimental study	259 residents	PHYSICAL ENVIRONMENT Small scale living facility	 Enabling	 Studied, significant
Voelkl, Fries, and Galecki, 1995 [22]	Study on predictors of nursing home residents (with and without cognitive problems) participation in activity programs based on Lawtons model on antecedents and consequences of older adults' activity participation	Cross sectional study	2.672	RESIDENTS Use of care resources Female gender Better cognition Depression Sense of initiative ACTIVITY OFFER Activity repertoire / preference Location preferences – preference to stay in room	 Disabling Enabling Mixed Disabling Enabling Enabling Disabling	 Studied, significant Studied, significant Studied, significant Studied, significant Studied, significant Studied, significant Studied, significant

Voelkl, Winkelhake, Jeffries and Yoshioka, 2003 [21]	Study on the use of the nursing home environment of residents and staff, and on staff perceptions on predictors, barriers and affordances of residents' engagement in activities.	Case study using observations and focus group interviews with staff	42 residents 12 staff	RESIDENTS Better cognition Better physical abilities Personal preferences Resident perceptions such as shame Lack of communication abilities Depression STAFF RATIO Staff turnover CARE CULTURE Task oriented staff philosophy ACTIVITY OFFER Variety in activities Lack of recreational resources Routine Difficult working relationship care and recreational staff PHYSICAL ENVIRONMENT Physical environment – inviting environment for residents, appropriate furniture. Adjusted to needs and preferences	 Enabling Enabling Enabling Disabling Disabling Disabling Disabling Disabling Enabling Disabling Disabling Disabling Enabling	 Study result Study result Study result Study result Study result Study result Study result Study result Study result Study result Study result Study result Study result
Vollicer *et al.*, 2006 [3]	Study on the effects of continuous activity programming on behavioral problems	Observational	90	STAFF RATIO Low staff ratio ACTIVITY OFFER Knowledge on activity provision Activity provision by all staff, not only activity staff Continuous activity program instead of traditional activity schedules	 Disabling Enabling Enabling Enabling	 Studied, confirmed Study result Study result Studied, confirmed
Wood *et al.*, 2005 [84]	Study on routine activity situations on an Alzheimer's disease special care unit concerning time use, interactions and affect	Case study	7	CARE CULTURE Skills of staff to recognize activity need PHYSICAL ENVIRONMENT Background media Making use of activating environment	 Enabling Disabling Enabling	 Study result Study result Study result

Wood, Womack and Hooper, 2009 [38]	Study to explore interrelationships among routine activity situations on 2 SCUs and daily time use and emotional well-being	Case study	14	CARE CULTURE Lack of understanding importance of occupation Insufficient attention to resident's occupational needs, initiatives and capabilities Low levels of staff-resident interactions PHYSICAL ENVIRONMENT Background media ACTIVITY OFFER Focus on activity schedules instead of everyday occupation Absence of activity staff	 Disabling Disabling Disabling Disabling Disabling Disabling	 Study result Study result Study result Study result Study result Study result
Zimmerman *et al.*, 2005 [16]	Study on which elements of long term dementia care are related to resident quality of life. Outcomes reported: higher score on QoL in AD-Activity and / or Type 1 behavior category codes considering to be good behaviors in DCM	Cross sectional study in 45 facilities using patient reports, staff reports and dementia care mapping observations	421	RESIDENTS Age Gender Race Marital status Length of stay < 12 months Better cognitive status No behavioral symptoms Less functional impairment Comorbidity Depression Ungroomed or inappropriate appearance STAFF PERCEPTIONS Work satisfaction Work stress Perceived success in treatment of residents	 Neutral Neutral Neutral Neutral Enabling Enabling Enabling Enabling Disabling Disabling Disabling Enabling Disabling Enabling	 Studied, n.s. Studied, n.s. Studied, n.s. Studied, n.s. Studied, confirmed Studied, confirmed Studied, confirmed Studied, confirmed Studied, n.s. Studied, confirmed Studied, confirmed Studied, confirmed Studied, n.s. Studied, confirmed

				STAFF RATIO		
				Stability of provider-resident assignments	Disabling	Studied, confirmed
				Staff turnover	Disabling	Studied, confirmed
				Ratio receiving professional or unprofessional treatment	Enabling	Studied, confirmed
				Formal staff training	Enabling	Studied, n.s.
				CARE CULTURE		
				Approach to people with dementia	Enabling	Studied, confirmed
				Policies and practices (policies on admission, discharge, and problematic behavior)	Disabling	Studied, n.s.
				Involvement of physicians or paramedics in care planning	Enabling	Studied, n.s.
				Resident assessment	Enabling	Studied, confirmed
				Positive communication / interaction with staff / physical contact / positive person work	Enabling	Studied, disproved
				Use of cholinesterase inhibitor	Enabling	Studied, confirmed
				Use of antipsychotic or sedative hypnotic	Enabling	Studied, confirmed
				Observed in restraints	Disabling	Studied, confirmed
				ENVIRONMENT		
				Facility type (traditional or new model, large or small scale, for or non-profit)	Neutral	Studied, confirmed
				ACTIVITY OFFER		
				Family involvement (hr / week)	Enabling	Studied, n.s.
				Specialized worker perspective	Disabling	Studied, n.s.
				Encourage activities	Enabling	Studied, n.s.
				Use of stimuli	Enabling	Studied, n.s.

Chapter 8 – General discussion

Seize the day!

1. Introduction

The first aim of this study was to clarify the relationship between activity involvement and daily occupation[i] of care home residents with dementia on the one hand, and their wellbeing and quality of life on the other. Our second aim was to study whether there was a relationship between various characteristics of the dementia care home environment and daily occupation and activity involvement of dementia care home residents. In the existing literature, activity involvement and daily occupation have been described as an important need for people with dementia[e.g. 1-3], yet researchers have consistently found a lack of stimulating activities in dementia care homes[4-6,]. With our research, we aimed to provide more insight into the potential of activity involvement to improve the wellbeing of care home residents with dementia, including residents with severe cognitive impairment, and to identify potential barriers and facilitators in the nursing home environment for the involvement of residents in activities and daily occupation.

In the current chapter, our findings are summarized and discussed, by answering the main research questions of this thesis. Methodological considerations are addressed, and recommendations for clinical practice, health care policy and future research are presented.

2. Summary of the main findings

Research question 1:
To what extent is the involvement in activities and daily occupation related to the quality of life and wellbeing of people with dementia living in care homes? Is this relationship different for people at different stages of dementia?

Activity involvement is beneficial for the overall quality of life of care home residents with dementia

In this thesis, we found that overall, residents who were involved in activities for more than three hours over the course of three days (defined as higher activity involvement), had a better relationship with their professional caregivers compared to residents who were less involved in activities. They also had a more positive mood, less restless behavior, better social relationships with other residents, and they had something to do more often.

However, higher activity involvement was also related to a less positive self-image and more social isolation of residents, as compared to those who were involved in activities for less than three hours over the course of three days (chapter 4).

[i] We have defined *Involvement in activities* as engagement in recreational and leisure activities. Examples are physical exercise, painting, group conversations, singing, and board games.
Daily occupation for people with dementia entails more than activity involvement. Occupation refers to involvement in recreational and leisure activities, but it also includes having a meal, receiving physical care, taking interest in a stuffed animal, watering flowers, helping others, social conversation, and so on.

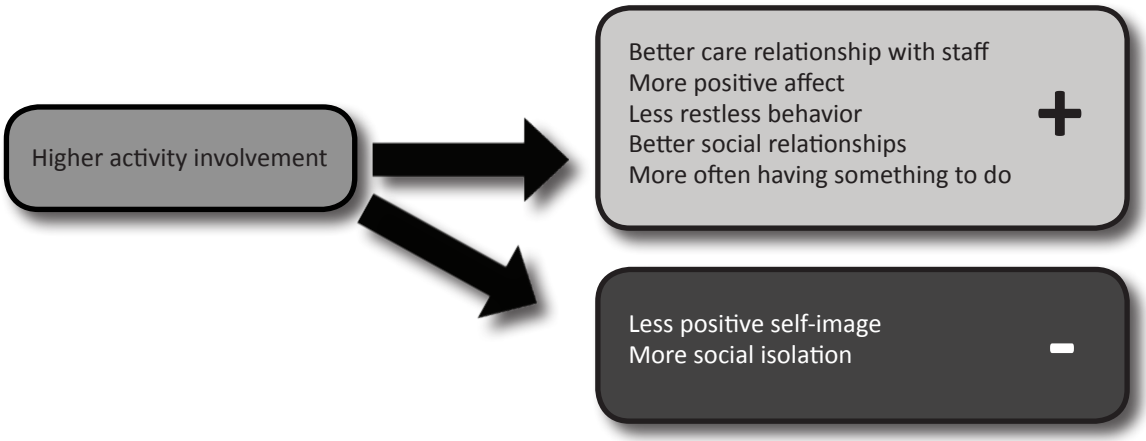

Figure 8.1: the relationship between higher activity involvement and domains of quality of life

Certain types of daily occupation are related to higher wellbeing, others are not

Trained researchers observed that residents who were involved in reminiscence, leisure, expressive and domestic activities experienced higher levels of wellbeing than when they were involved in other types of occupation. The former were defined as 'wellbeing-enhancing occupation'. It must be noted that physical exercise, a type of occupation that has been found to positively influence wellbeing in earlier research[7,8], did not take place during the observations in our study (chapter 3).

In our research using staff observations (chapter 5), we found that the occupation types 'having visitors, playing games, physical exercise or sports, reminiscence, and conversation' had the strongest relationship with wellbeing. Engaging in domestic tasks, expressive activities and mind exercises were also related to wellbeing but to a somewhat lower degree. Eating or drinking, and listening to music or watching TV only had a minor positive relationship with wellbeing.

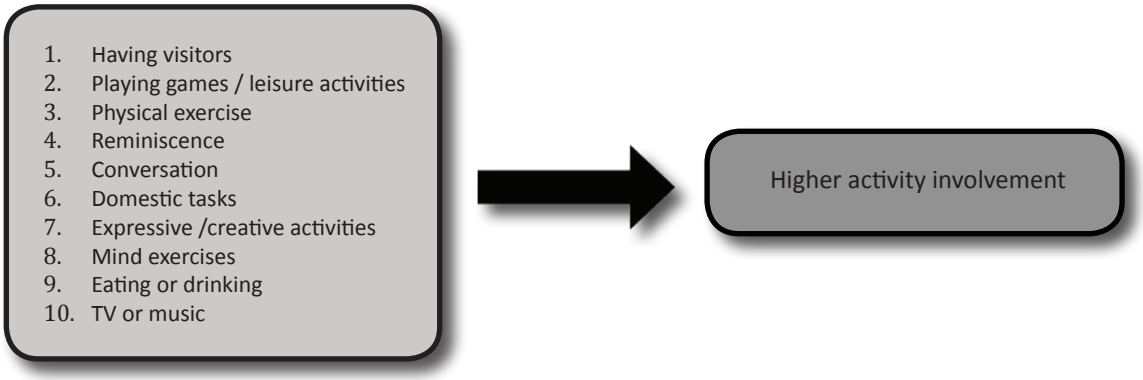

Figure 8.2: Overall ranking of the types of occupation that relate to higher wellbeing (from highest to lowest impact on wellbeing)

Involvement in activities and daily occupation is also important for residents with severe dementia

In this study, residents with severe dementia and a higher activity involvement showed a higher quality of life, especially with respect to positive affect and restless behavior (chapter 4).

In our sample of residents with severe dementia, several types of types of daily occupation were related to a higher wellbeing as observed by staff, but the types of occupation that were related to wellbeing were different than for people with less severe dementia. In people with severe dementia, eating or drinking seemed to have become more important, as did 'looking around'. The impact of conversation, receiving visitors, and physical exercise or sports, was less important for the wellbeing of residents with severe dementia than for the wellbeing of residents with fewer disabilities (chapter 5).

Table 8.1: Ranking of the types of occupation that related to higher wellbeing (presented from highest to lowest impact on wellbeing) across three groups of residents divided according to their cognitive status, as observed by staff

	Mild - moderate dementia[1]	Moderate-severe dementia[2]	Severe-very severe dementia[3]
Types of occupation related to higher wellbeing	1. Having visitors 2. Playing games 3. Physical exercise 4. Reminiscence 5. Conversation 6. Creative activities 7. Domestic tasks	1. Having visitors 2. Religious activities 3. Playing games 4. Domestic tasks 5. Physical exercise 6. Reminiscence 7. Conversation	1. Playing games 2. Reminiscence 3. Looking around 4. Eating and drinking

[1]CPS score 0 to 3; [2]CPS score 4; [3]CPS score 5 or 6

Although there is much variation between and within care homes, overall it can be said that there is only occasional involvement of dementia care home residents in activities or wellbeing-enhancing types of occupation.

In this study, we found that - despite the increased awareness of the need for meaningful activities in the literature and long term care policies – residents were not often engaged in types of occupation or activities that related to higher wellbeing.

Regarding duration of activity involvement, there was considerable variation in involvement in activities between residents, also within care homes. Overall, 38.8% of the residents were involved for less than one hour over the course of three days, 30.2% were involved for one to three hours, and 31% for more than three hours (chapter 4; see figure 8.3 for the distribution of hours of activity involvement of the residents in our sample).

With respect to daily occupation, types of occupation that were found to be related to wellbeing ('wellbeing-enhancing occupation') were observed in less than 5% of the timeframes on average. These observations were conducted by trained observers (chapter 3). Again, we found much variation between care homes participating in this study in engaging the observed residents in wellbeing enhancing occupation. In one care home, residents were engaged in wellbeing enhancing occupation during 25% of the observed timeframes on average. By contrast, in a second care home, the figure was less than 1% (chapter 3).

In our study using staff observations, we found that residents were sleeping, eating or drinking, talking with staff or other residents, or looking around doing nothing for 84% of the observed one-minute time frames. Again, we found that types of occupation that strongly related to wellbeing, were infrequently offered (chapter 5).

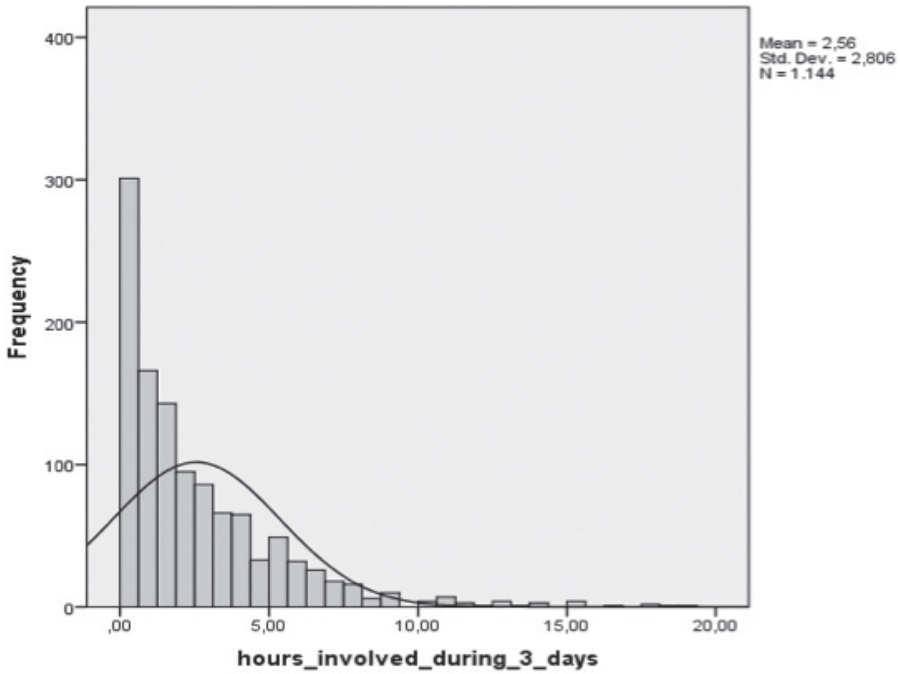

Figure 8.3: the distribution of hours of activity involvement of the residents in our study sample (n=1144)

<u>Research question 2:</u>
Which characteristics concerning residents, environment and staff of the care home influence activity involvement and daily occupation?

Disease-related and socio-demographic characteristics strongly influence the residents' level of activity involvement

Physical and cognitive limitations and agitated behavior had a strong, negative impact on duration of activity involvement of care home residents with dementia (chapter 7). Behavioral symptoms physical limitations, as well as age and gender of residents were also associated with the involvement in fewer different types of activities (chapter 6).

Also, in our data derived from staff observations, we found that residents with more severe cognitive and physical limitations, were less involved in types of daily occupation that were associated with higher wellbeing (chapter 5).

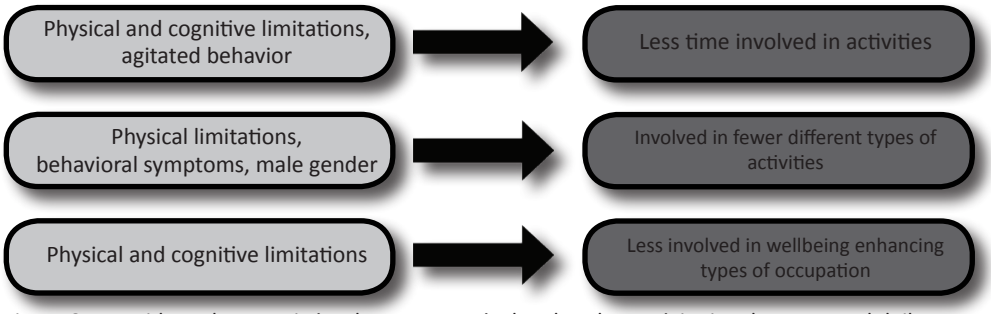

Figure 8.4: Resident characteristics that are negatively related to activity involvement and daily occupation

Small-scale group living home care facilitates the activity involvement of dementia care home residents

The implementation of more characteristics of small-scale group living home care (like having a home-like atmosphere, the preparation of meals in a normal kitchen that is accessible for residents, and residents having a say about when they get out of bed) was related to involvement in more types of activities in general as well as in preferred activities. Residents of care homes with more characteristics of group living home care were more involved in task-related activities, outdoor activities, leisure activities, physical exercise, and interaction with others. The number of residents living at the total facility site was not related to involvement in more types of (preferred) activities (chapter 3).

We found that a smaller number of residents in the total facility predicted more time of activity involvement (more than one hour a day) among care home residents with dementia. A higher number of group living home characteristics was also related to more activity involvement, yet these characteristics were found to have a weaker relationship with activity involvement than the scale of the facility (chapter 6).

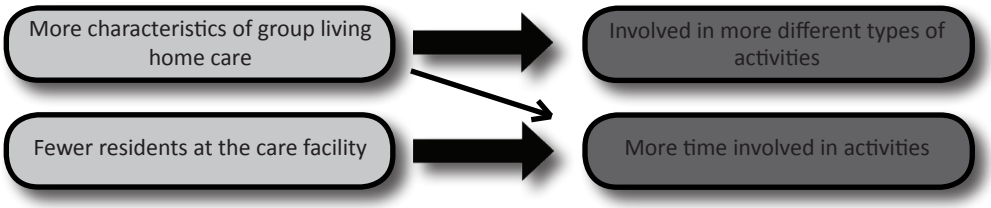

Figure 8.5: The positive relationship between small-scale group living home care and activity involvement

A stimulating environment increases the residents' involvement in activities and daily occupation

Based on our resident observations, we found that care homes that frequently engaged their residents in wellbeing-enhancing types of occupation, more often had a home-like atmosphere, supported social interaction through the environment, and did not have a central activity program (chapter 3). Studying predictors of duration of activity involvement among people living in dementia care homes, we found a small negative impact of offering activities in a club-wise arrangement. The presence of a central activity program had no impact on activity involvement. (chapter 7)

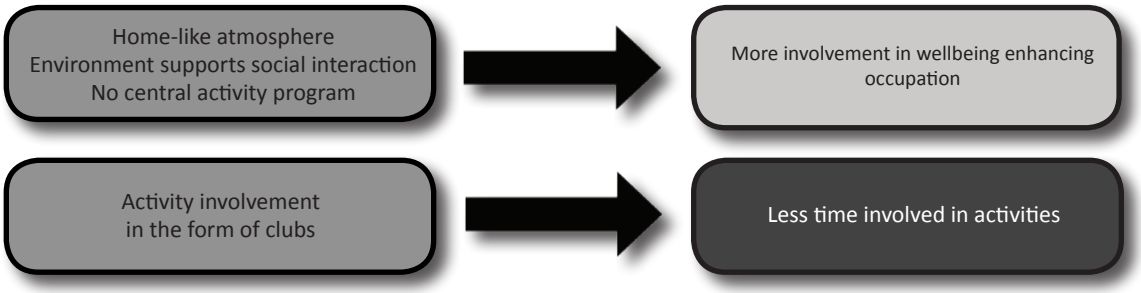

Figure 8.6: Environmental features that relate to daily occupation and activity involvement

Staffing levels and the perceived job demands of staff are important predictors of activity involvement

In this study, we found that a higher educational level of care staff was a main predictor for more time spent in activity involvement among dementia care home residents. The quantitative staffing levels (or staff ratios) were also found to be related to higher activity involvement, but proved to be of less influence than educational level. The percentage of care staff with a higher educational level, and staff ratios varied considerably between the care homes in our study. The percentage of staff with educational level 3 or higher ranged from 23% to 100%, whereas the staff ratios ranged from 14 to 31 hours of care staff a week per resident. Educational level and staff ratio were not inter-correlated (implying that a low staff ratio was generally not compensated by higher educated staff, or vice versa).

Moreover, higher job demands (or a higher workload) as perceived by staff were found to be a main (negative) predictor of activity involvement by residents. Contrary to our expectations, also higher social supervisor support as perceived by staff was an important negative predictor of residents' activity involvement. The same (weak) relationship was found for transformational leadership and activity involvement.

Other characteristics that were found to relate to activity involvement but were only of minor influence were: more involvement of family caregivers in the decisions and procedures in the care for their relative, greater unity in care philosophy, and more help from volunteers at the facility (chapter 7).

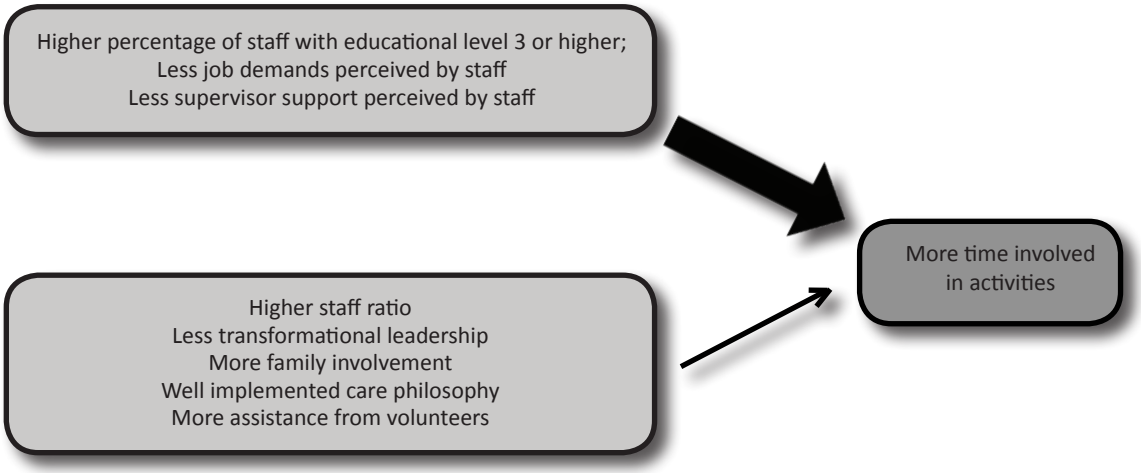

Figure 8.7: Characteristics of the organization and culture of the care home that predict activity involvement

3. Reflections on the findings

Our findings show that the involvement in activities and daily occupation by people with dementia living in care homes should receive a prominent place in care practice in which maximizing the psychological wellbeing of the residents is a primary goal. Previous research already showed that people with dementia considered meaningful activity engagement as one of their core needs[1,9,10]. This need was found to be largely unmet among care home residents with dementia[3,4,6,11]. Our findings show that occupation and involvement in activities are more than a luxury wish for people with dementia. They are related to various aspects of quality of life and wellbeing and can therefore be perceived as a basic need. This also holds for people with severe cognitive limitations.

This conclusion is consistent with the recommendations of the World Health Organization (WHO)[12]. When applied to the WHO's Healthy Aging model, our results suggest that by facilitating activity engagement or occupation among its residents, the care environment has the potential to compensate for the functional and cognitive losses of people with dementia that negatively influence quality of life. Activity involvement or meaningful occupation may improve functioning, resulting in higher psychological wellbeing. Thus, care homes must take responsibility for facilitating higher activity levels among their residents.

That said, one might argue that the relative impact of activity involvement on quality of life was modest compared to the impact of disease related characteristics. However, we found that most of the residents were involved in activities for less than one hour a day. Because duration of activity involvement was not normally distributed, as illustrated in Figure 8.3, we were not able to use it as a continuous variable. By dichotomizing the variable, we had to define 'higher activity involvement' as 'involvement for more than three hours over the course of three days'. In other words, most residents who comprised the 'higher activity' group, were still unoccupied for the largest part of the day. It is entirely possible that the effect of activity involvement on quality of life would be much higher if we were able to compare low activity involvement with activity involvement for a more substantial part of the day.

The low levels of activity involvement and wellbeing enhancing types of occupation among dementia care home residents imply that there is much room for improvement in care homes. In our study, we found considerable variation in activity levels of residents between care homes. Consistent with the literature[13-16], differences in staff education, experienced workload and staff ratio seem to be largely responsible for this variation. Furthermore, while no clear positive effect was found for small-scale group living home care and residents' quality of life in previous studies[17-20], a home-like, small-scale care environment that embodies characteristics of group living home care does lead to higher levels of occupation and activity involvement. The extent to which the opportunities of a group living home care environment are actually used to stimulate and activate its residents might be a key aspect for group living home care to be effective[21]. The fact that the size of a care home is an important predictor of activity involvement by residents might indicate that, within larger care facilities, it is more difficult to make the transition towards a care philosophy with a focus on wellbeing and person-centeredness, with attention for activities and occupation. In our study we found that a well-implemented care philosophy and the involvement of family caregivers in the care for their residents facilitate activity

involvement. All these components point to the need for a culture shift in certain care homes. In order to meet the need for activity involvement, the principles of small-scale group living home care must be embraced, leading to more person-centered care, and strong cooperation with family caregivers. Moreover, care facilities must review their use of the available financial means, in order to reach higher staffing levels with better educational levels.

However, there was also much variation in the involvement in activities or wellbeing-enhancing types of occupation of residents within the same care home. Resident characteristics are largely responsible for this variation, consistent with previous research [e.g. 22-26]. These findings address the need to improve the skills of staff to engage residents who have more complex care needs[27]. Furthermore, our findings teach us that certain types of occupation are more important for residents' wellbeing than others. While it is always important to adjust activities to personal preferences and interests[28,29], knowing that in general, physical exercise and reminiscence are more important for wellbeing than for example having a conversation, helps staff to use the available time most effectively.

4. Methodological considerations

4.1 The Living Arrangements for People with Dementia (LAD-) study

In this thesis, data of three measurement cycles of the LAD-study were used to study activity involvement and occupation of residents with dementia living in care homes (2008 – 2014).

The main strength of this study is its broad scope in terms of research settings, participants and measures. In the first two measurement cycles, data were derived from 136 and 144 settings throughout the country, representing around 10% of the dementia care homes in the Netherlands. Data were obtained from 1,327 and 1,389 residents in total. With the selection procedure, we ensured that the five dominant types of nursing home care for people with dementia in the Netherlands were represented, ranging from large-scale traditional nursing homes to small-scale group living home facilities. Therefore, it is likely that these large samples have led to generalizable results. The large sample sizes also made it possible to use advanced statistics which enabled us to correct for variance found between individuals that should be attributed to differences in care settings (clustered data). Because in the third measurement cycle, fewer care homes participated (n=54), the generalizability of the findings may have decreased.

With the LAD-study, a wide range of data was collected, covering organizational characteristics, as well as environmental features, staff experiences, resident wellbeing, indicators of quality of care, and family perceptions. This enabled us to study relationships regarding variables derived from different sources.

A limitation of the design of the LAD-study is its cross-sectional character. Cross-sectional data give no certainty about the causality of the relationships found. Although the studied relationships were based on clear hypotheses to minimize this chance, we cannot rule out that it is also possible that higher quality of life resulted in higher activity involvement instead of the other way around. The proposed direction of the relationship between activity involvement and quality of life was confirmed however by our Dementia Care Mapping and staff observations of the daily occupation and wellbeing of residents with dementia. With these observations, the direct impact of occupation on wellbeing was observed repeatedly.

4.2 Measurement instruments for activity involvement and occupation

In this thesis, three different instruments were used to obtain data on the involvement in activities and occupation of care home residents with dementia. Each instrument suffers from limitations. The strength of this research lies in the combination of the three instruments, that

together give a clear insight into the current status of activity involvement and impact on wellbeing.

1. *The Activity Pursuit Patterns (APP)*

For obtaining information on residents' involvement in activities, the Activity Pursuit Pattern (APP) instrument, developed for the Minimal Data Set (MDS)[30], was used. Little information was available about the psychometric properties of this instrument[31-33]. Before applying it in the first measurement cycle of the LAD-study, we had no experience with this instrument. We came across important limitations. We found that in using the original APP, only the number of activities the person was involved in could be studied in our sample, and not the extent to which a resident was involved in this activity. Although the APP used in the MDS also includes a question on how much time the residents are involved in activities during the day, this question was not accurate due to the broadness of the answer categories ranging from 'not involved', 'involved for 1/3 of the day', 'involved for 2/3 of the day', to 'involved almost all day'. Almost all residents in our sample were classified by staff as being 'involved in activities for 1/3 of the day'.

For this reason, we extended the APP in the second measurement cycle of the LAD-study with a time variable. Again, we discovered limitations in using this instrument. First, the fact that many data were missing in questionnaires raised the question whether staff were able to reliably recall what residents had done during the past three days; even more so, because they might not have worked the last three days, making them dependent on reports or observations of colleagues. It is likely that our retrospective research method has resulted in an estimation of the time residents are usually involved in the listed types of activities as perceived by the care staff, instead of accurate daily records. Secondly, staff sometimes seemed to be unable to discriminate between active and passive activity involvement, which may have resulted in an overestimation of activity involvement. For example, there is a difference between sitting in a room where the radio is on (passive involvement), and actively listening to one's favorite music (active involvement). For the activities talking, watching television and listening to music or radio, the reported time of involvement was at times so extreme – some people were found to be involved in watching television for more than 24 hours during the past three days – that they had to be excluded from analyses to improve the validity of the findings. It is imaginable that the same problem also occurred for other types of activities, without being clearly visible in the data.

2. *Dementia Care Mapping (DCM) observations*

Dementia Care Mapping is sometimes questioned as a research tool since it was primarily developed to evaluate and improve care practice[34]. Although the observation technique is standardized and performed by trained observers, it has certain psychometric limitations, such as low variability and low inter rater reliability in the wellbeing code[5]. Despite these limitations, DCM can measure behavior and wellbeing simultaneously, enabling the study of the relationship between both in detail. The method is costly however, and the presence of the dementia care mapper might have influenced the observed behavior of both residents and staff.

In 2010, an in-depth study was performed in 10 care homes that participated in the LAD-study. The general aim was to look closer at the reason why these care

homes scored particularly high or low on outcomes of staff wellbeing, quality of care and quality of life. Dementia Care Mapping observations were used to generate information on activity involvement and wellbeing in this study[35]. Although the sample size of the observed residents was rather small, with the DCM method we tried to capture the experience of care from the perspective of the residents with dementia using standardized methods.

3. *Staff observations on occupation and wellbeing*

To our knowledge, we were the first to use staff observations of the occurrence of occupation amongst residents during their shift. The instrument we used was based on behavior and activity types of the DCM and APP instruments. The instrument was easy to use amongst care staff and more accurate than the APP, and could therefore constitute a feasible alternative for collecting data on activity involvement and occupation in large-scale research. After receiving a one-hour training, observations were performed in 50 of the 54 participating care homes. However, staff often reported more than one type of occupation during one minute of observation. It may be better to instruct staff to choose the dominant type of occupation perceived in one minute, because noting several types of occupation can lead to an overestimation of the effect of less meaningful types of occupation. For example, when someone participates in a reminiscence activity while having a cup of tea, we suspect that wellbeing is mainly influenced by the reminiscence activity rather than drinking tea. Furthermore, more research is needed on the instrument's intra- and interrater reliability, and whether the fact that the observations are conducted by care staff who are also providing care at the same time influences the data. For example, more activities may be initiated during their observations, or because staff might tend to report that people enjoy the activities that they organized themselves. Also, there is room for improvement with regard to the description of the occupation types that were listed.

4.3 Measurement instruments for resident characteristics

To obtain information on the characteristics of residents concerning their level of functional and cognitive impairment, standardized instruments on physical limitations and cognition were filled in by a professional caregiver who was familiar with a particular resident. For some instruments, it has been recommended that the questionnaires concerning these elements should be completed by two individuals[36,37]. For feasibility reasons, we sent the questionnaires to one staff member per resident. We were not able to provide the staff with intensive training on how to use the instruments. With the data-cleaning process, we found certain peculiarities in our data. For example, about 1 percent of the sample had a Cognitive Performance Score of 0, indicating that there were no signs of cognitive problems. Since the persons participating in this study all lived in dementia care units based on a diagnosis of dementia or other cognitive problems, a score of 0 is questionable. A possible explanation may be that the type of dementia does not immediately cause cognitive problems that are detected by the CPS (as can be the case with Frontal Lobe Dementia, where memory problems and difficulties with time and planning occur later in the disease process, while substantial behavioral changes can cause a person to need constant guidance and care).

However, to obtain more insight into the use of the CPS instrument by care staff, Dieneke Smit (currently working as a director of a dementia care facility – that was not involved in our study) asked some care staff members to fill in the CPS on residents known to have substantial cognitive problems. Care staff filled in the questionnaire in pairs. Dieneke noticed that some staff members greatly overestimated the cognitive abilities of residents as proposed by the CPS. For example, with the CPS item of the third subscale (concerning expression), care staff sometimes filled in the answer category 'the person is understood', indicating that there were no problems with making

oneself clear. Talking about this, they explained that they knew this resident well, and always understood what she meant. Also with the wayfinding item of subscale 2 of the CPS (answer categories memory problems yes or no), they argued that with a little bit of help, the person always knew the way to her own apartment and thought that the answer was 'no cognitive problems'.
From this experience, we hypothesize that a very person-centered attitude of care staff possibly causes them to overestimate the actual abilities of residents.
Thus, having the CPS be filled in by care staff, may have influenced our study data. The fact that care staff were asked to fill in the questionnaire on resident characteristics individually instead of in pairs in our study, might have been of influence. But in our 'experience', we found that even pairs of care staff could fill in the questionnaire in another way than intended .
These observational measurement instruments might need a more clear instruction, or staff members should be trained in how to fill in the questionnaire before use.

5. Implications for practice and health care policy

Several recommendations for health care practice and policy can be made based on the results of the research conducted in this thesis.

5.1 A change in perception of the content of nursing home care is needed: involving residents in activities is just as vital for resident wellbeing as providing physical care

Traditionally, the nursing home environment was primarily focused on the physical care and medical treatment of residents with dementia. In recent decades, care professionals have recognized the value of a person-centered approach for the individual resident, with a focus on wellbeing. Our findings reveal the large potential of involvement in activities for several outcomes of quality of life for residents with dementia. We therefore recommend that involvement in activities should be perceived as a core element in long-term dementia care. Since involvement in activities by the residents in our study samples was generally low, we think there is much to gain when it comes to wellbeing. To implement activity provision in dementia care practice, we present the following recommendations.

Care managers need to include meaningful occupation in the care home's care philosophy

It has been stated that the low involvement in activities by residents with dementia is mainly attributable to the lack of value care professionals accord this issue with respect to a resident's wellbeing[14,38]. If care managers truly want wellbeing enhancing occupation or activity provision to become a key aspect of the care for residents with dementia, this should be addressed accordingly in the care homes' care philosophy.
In previous research, a clear care philosophy for staff, management, as well as family, was found to be a key factor in providing high quality care, because it serves as a guide in how to deliver care, and it provides answers in difficult situations[39]. Having a clear care philosophy ensures that all those involved in the care for people with dementia serve a common goal and have common standards on how this care should look. A care philosophy only serves its purpose when it is well implemented.

This means that care staff must be aware of the care philosophy and be taught how to work accordingly. The daily work should be discussed in alignment with the care philosophy on a frequent basis[39].

Every staff member providing direct care for residents should facilitate activity involvement

We advocate that activities or meaningful occupation should (also) be provided by the regular care staff, and not solely be the responsibility of recreational or activity workers. Therefore, regular care staff should learn how to integrate meaningful activities or occupation in the daily care for their residents, even when residents have complex care needs (see also 5.3).

In our study, we noticed that having a central activity program or activities provided in clubs, might result in lower activity involvement. We suspect that these elements result in regular care staff not feeling responsible for activities other than specially organized activities[40].

Attracting not only Certified Nursing Assistants or Registered Nurses to provide the daily care to residents, but also staff with a wellbeing-oriented background such as a recreational worker or social worker, might make it easier to incorporate activity provision into daily care practice. As was described in the literature, it is helpful to combine staff with various education backgrounds so that both the physical and the emotional aspects of long-term care are taken into account in the normal living environment of residents[41].

Meaningful occupation can best be admitted as a core goal in the personal care plan

In our study, we found that a large proportion of the observed residents were involved in hardly any activities throughout the day (38.8%). A good way to increase awareness of the need for occupation on a daily basis, might be to include meaningful occupation (adjusted to one's preferences and abilities) as one of the core goals of a resident's personal care plan.

In the Netherlands, working with a personal care plan for each resident is a quality demand by the Dutch Healthcare Inspectorate[42]. This personal care plan must contain the primary goals regarding care for the person with dementia, that reflect the needs and wishes of the resident and his or her representatives (instead of primarily focusing on disease-related problems). In many care homes, care staff keep these goals in mind when writing their daily resident reports.

The responsibility of care homes to provide meaningful occupation to their residents should be addressed in healthcare policy

In order to substantially increase activity involvement and occupation among residents with dementia, we recommend that care homes be stimulated in this respect by governmental support and regulations. The limited attention to activities by care homes and the need for the development of skills amongst care staff, as our results point out, have recently been recognized by the Dutch government[43]. Care homes are receiving substantial subsidies when they stimulate activity provision by their care staff, during the period from 2016-2020. Furthermore, meaningful occupation is also integrated in the new 'Quality framework'[42] that has been developed and commissioned by the Dutch government. With this Quality framework, care homes are required to report on the way they address the need for meaningful occupation for their residents in their annual reports. Presumably this will also be checked by the Healthcare Inspectorate. The Dutch Healthcare Inspectorate is currently developing a new way of measuring quality of care within care homes[44]. Instead of checking mainly procedures and protocols, they also try to obtain information about the actual care, guidance and attention that is provided by the care home. Hopefully, these developments will lead not only to increased recognition of the importance of activity provision, but also to increased sustainable knowledge and skills among care staff in this field.

5.2 Knowing the residents is a precondition for activity involvement that is aligned with the person's needs

In order to offer appropriate activities to more impaired residents, care staff must be aware of the cognitive and functional abilities of each individual resident[15,28,45]. Also, a more person-centered attitude among staff, knowing more about the resident's life history, specific interests, and preferred activities, might result in a better suited activity program[46].

In our study, we found that people with more severe dementia benefitted from other types of occupation than residents who were less cognitively impaired. In addition, more physical limitations predicted lower activity involvement. And residents with agitated behavior were found to be less involved in activities than residents without these behavioral symptoms. Research has shown that when activities are tailored to the individual functional level (for example, using larger ball or a balloon in a ball game, or transferring from verbal into nonverbal communication or singing), residents who suffer from agitated behavior could stay involved[27].

We also found that being male was correlated with involvement in fewer types of activities. We suspect that the predominantly female care staff find it harder to engage male residents in activities. Increasing their knowledge on the personality and preferences of their residents would enable them to provide more suitable activities.

5.3 Care staff must be taught what meaningful occupation entails, and how to integrate activity provision within their daily work

Based on the results of this study, for the sake of the wellbeing of people with dementia, it is no longer acceptable that providing activities or facilitating meaningful occupation, plays little or no part in the education of care staff in the Netherlands. The training course for Certified Nursing Assistants (CNAs), Nursing Aids (NAs) or Registered Nurses (RNs) was – and still is – mainly focused on the physical care and guidance of nursing home residents. Providing activities is the specialism of trained activity or recreational workers. In many care homes, this task differentiation is still present. Not surprisingly, care staff perceive providing activities to be the task of the recreation worker[27], and the activity involvement of residents sometimes depends on the presence of such a colleague.

Engaging care home residents with dementia in activities requires knowledge, creativity and ideas to engage people with severe functional limitations and who are less capable of initiating activities themselves, in a meaningful way [29,47]. To increase involvement in meaningful activities or occupation, we therefore recommend that care staff should receive more training on the job and in college, on how to make occupation meaningful, i.e., aligned to the residents' needs, and how to offer or facilitate this.

<u>Facilitating activity involvement and meaningful occupation should be included in the education program of RNs, NAs and CNAs</u>

Although colleges try to place a larger emphasis on wellbeing in their curriculum

for their nursing education programs nowadays, they still inadequately address the provision of meaningful occupation or activities in general. Where students did receive lessons on activity provision, we found the program to be outdated, focusing on traditional group activities that are not adjusted to the individual needs and functioning level of residents[48]. There is a gap between skills that are needed in care practice, and skills that are being taught. Teachers often have little working experience of care practice, or may have left care practice years ago when there was little knowledge of or attention for the psychological needs of care home residents with dementia. Moreover, colleges do not seem to base their curriculum on the latest knowledge available. To address the need for more multitask care staff in care practice, colleges are merging different education profiles to create professionals who can both provide physical as well as emotional care and are focused on wellbeing[49]. However, we believe that the care students' knowledge level can be further improved by better awareness of the 'state of the art of dementia care'. At the same time, care professionals should be aware of the curriculum and willing to help develop it, thereby building bridges between practice and theory[50].

Current care staff of dementia care homes should be trained in meaningful activity provision as well

To change care practice, the current care professionals should be educated to provide or organize meaningful occupation for their residents[16]. Many staff who had no training in activity provision, feel uncertain about facilitating meaningful occupation and activities. They need to know what constitutes meaningful occupation for people with dementia, expand their knowledge on creating personally meaningful activities, and on how to offer these activities to the individual residents within their capabilities[47]. With this knowledge, care staff will become equipped to spend their time in a more beneficial way in terms of resident wellbeing. An example that emerged from our study was that without spending extra time, care staff could engage in reminiscence instead of merely making small talk, with a positive impact on wellbeing.

Secondly, with the overall increasing care dependency of residents in long-term care homes, it is important to train care staff in assessing the capabilities and interests of residents, and to develop activity skills accordingly. Our findings suggest that residents with severe dementia still benefit from activity involvement. However, we found that activity levels were far lower among people with severe dementia. Engaging severely impaired residents in activities requires expertise and the use of adapted materials, based on the (limited) capabilities that are preserved[29,45,47]. Literature shows that by training care staff to adapt activities to the needs and wishes of people with dementia, the wellbeing and functioning level of residents improved, and the use of psychotropic medication decreased[51].

Furthermore, staff have to acquire skills on how to use the environment (see 5.4), and make activity material available for their residents. This also includes knowing how to actually use material for activities for residents with different preferences and functioning levels (for example physical exercise, sensory stimulation, reminiscence activities, music activities).

In addition, staff must learn to integrate physical care with meaningful occupation when the resident's care demands increase; for example, by singing, playing someone's favorite music, or giving a massage while bathing. It is about making contact, and taking the time to do so[47].

Most importantly, the care management has to facilitate the change towards activity provision and create a supportive environment for this purpose. New knowledge does not in itself lead to a real change of practice. Whereas a proper training program is important, change of practice depends on the staff's motivation to adequately follow the program, use the derived knowledge, and feel the confidence and support to apply it in practice[52].

5.4 Care homes should become a stimulating environment that lowers the threshold for staff to provide activities

We recommend that care homes should create a stimulating environment (in terms of a home-like ambiance, an accessible kitchen, pets to care for, an aquarium to look at, magazines, old photographs, a radio playing old and familiar tunes) that lowers the threshold *for staff* to engage residents in an activity.

People with dementia lose the ability to initiate activities on their own. They need verbal or visual cues to be involved in occupation[53]. It is suggested that activity involvement might be improved by alterations to the physical environment which facilitate active participation of residents in household activities[54]. In this study, we found that an environment that stimulated social conversation (by the arrangement of furniture), and a homelike environment seemed to contribute to higher activity levels.

Furthermore, based on the preferences and functioning level of the individual residents of a dementia care unit, material should be purchased or collected from the resident's former home to create the most suitable environment for the current group of residents of the dementia care unit.

However, a small sample study by Wood et al.[21] showed that residents with dementia were not more active in a more stimulating environment because staff did not offer the material. A proper implementation of how to make use of the environment in order to stimulate residents should therefore not be overlooked.

Nursing home care can best be provided in care homes with smaller resident numbers and a homelike ambiance

Although in previous research, no direct relationship between small-scale group living home care and quality of life was found[17-19], our findings indicate that these facilities are beneficial for residents in terms of daily occupation and activities.

In this study, we repeatedly found that a care environment with more characteristics of group living home care was related to higher activity involvement. It seems the homelike environment might provide more opportunities for residents to be engaged in meaningful occupation[54], and make it easier to offer activities to residents as suggested above.

Although group living home care characteristics can also be implemented in a large-scale care home, we found evidence that higher levels of activity involvement among residents are present within smaller care homes. In the Netherlands, many care facilities try to offer group living home care in larger clusters of resident groups nowadays. Our data suggest that providing small-scale care within a large-scale setting, might not be a good alternative for the archetypal[55] small-scale group living home care in terms of their residents' occupation. Perhaps, providing care on a large scale makes it more difficult for the care facility to provide truly individually tailored care, based on the personal contact with residents and family caregivers. Furthermore, it is possible that making the transition from traditional medically oriented nursing home care towards a care home that is aimed at maximizing wellbeing, is harder to achieve in larger care homes. These care homes often have a long history of providing nursing home care for residents with dementia, and a transition would require enormous alterations in care culture and work style of both care staff and management.

Care homes should recognize the potential of technological devices to assist care staff in fulfilling the need for activity involvement

We recommend that care homes should make optimal use of the technological aids available that can help to pleasantly activate or stimulate their residents with dementia.

Our study findings point to the fact that many residents with dementia are unoccupied for large parts of the day, and that job demands as experienced by care staff result in lower activity involvement. Since in our data-cleaning process, we found residents to be watching TV for up to 8 hours a day, we suspect that this is a consequence of care staff often experiencing insufficient time to involve residents in activities.

Today, there are many technological devices available that can be used for activities with people with dementia. Examples are the robot seal 'Paro'[56] that reacts on being touched, by moving and producing sounds; the 'Tovertafel'[57] (Magic Table) that projects interactive virtual games onto a table; the 'CRDL'[58] that produces 20 different sounds types when two persons connect to the object that looks like a wooden baseball; the 'Qwiek-up'[59] that projects calming or familiar images on the ceiling, for example when receiving care on the bed; 'snoezel' bathtubs with bubbles designed for emotion-oriented care; but also simply laptops and tablets to Skype with family and play virtual games or look at photographs; iPods to play favorite music on a playlist; smart TVs to watch nostalgic programs and many more.

Three major objections arise regarding the use of these technological devices. First, most devices are costly. Second, people are afraid that these devices will replace the attention that staff can give. Third, people think that high tech devices do not fit with the altered perception of a person with dementia and therefore should not be used.

But taking into account the limited amount of time available to care staff to provide personal attention and activities, and the fact that devices can often be purchased using funds, they may be an excellent way to entertain residents with dementia when their caregivers are engaged with other residents. When the devices are implemented well and staff have learned how to use them, they can provide residents with *extra* meaningful types of activities, that are perfectly adjusted to the residents' functioning level and that are aimed at stimulation, activation or relaxation.

5.5 Cooperation with family members is essential for residents to 'continue to live their lives'

To maximize the wellbeing of care home residents with dementia, continuous involvement of their relatives is vital. Therefore, care homes must invest in this relationship.

The results of this study point to the importance of family involvement in the care for residents with dementia, in two ways. First, we found that having visitors was strongly related to the wellbeing of residents with dementia. It can be a challenge to keep family members involved in the lives of their relative. Visiting a relative with dementia is sometimes difficult for family members. Naturally, the past relationship with the person with dementia plays a role, as well as opportunities to visit, the relative's own health condition, transport possibilities, etc. But family members also struggle sometimes with the impact that the progressive dementia syndrome has on their relative, as well on co-residents, in terms of cognitive abilities and changed behavior. In order to keep family members involved, it is important to give them proper support and information to cope with the dementia process and accompanying loss. They also find it hard sometimes, to make contact with their relative, or do not know what to do during their visit. Giving relatives suggestions about what they can do, for example go on an outing, play a game, or help with preparing dinner, can make them more at ease in the contact with their relative[60]. It is also essential that relatives feel appreciated in the care home and feel welcome at any time.

Secondly, we found that both the level of involvement of relatives in decision-making about the care that is delivered, and better communication with relatives and staff, predicted higher activity

involvement. Meaningful occupation is seen as an important aspect of quality of care by family caregivers[5,6]. Their involvement in decision making might lead to a better advocacy regarding the provision of activities to their relative with dementia. Much can be improved in involving family in the care for relatives with dementia. In this case, the dementia care home sector still suffers from its history. Originally, the nursing home constituted a hospital-like setting where the medical staff controlled the treatment and care of their patients. Nursing homes took over the care from the family caregiver, and had set visiting hours[61]. Even today, family members are not always welcome at multidisciplinary meetings to discuss the care for the resident with dementia[62]. When a person with dementia moves into a care home, it should be explained to the family that they are essential in maximizing their relative's wellbeing in the care home. Family members are essential for informing the care staff about personal history, someone's personality, preferences, needs, and wishes. They must be assured that they are still involved in decision-making concerning the care for their relative. And with mutual responsibility, family members and care professionals must look for opportunities for visits or other moments of contact, and whenever possible, continue the activities that the client was used to do before moving to the care home.

5.6 Care homes should embrace the potential of volunteers and discover their needs and motivation in order to get and keep them on board

Under the right circumstances, the help of volunteers can substantially contribute to the activation and occupation of care home residents with dementia. This study showed that more hours of help from volunteers was related to higher activity involvement among care home residents with dementia. When financial and human resources are limited, the assistance of volunteers might be a good alternative to keeping residents involved in meaningful activities. Earlier, we found that there is much variety in the number and quality of volunteers available in care homes[39]. Many care homes were found to experience difficulties in finding and engaging volunteers. Care homes that were supported by numerous volunteers report that it requires creativity and reciprocity to attract and keep volunteers. This suggests that a culture change is needed: from care homes where volunteers are perceived as outsiders who come to contribute to the organization as a cheap workforce, to a place where they are truly part of the organization, where they feel welcome and where they contribute but also gain from their work; for example, by receiving opportunities to learn, experiencing being part of a team, deriving mental satisfaction, or receiving support in a job finding process.

5.7 Care staff must be supported in the increasing care needs of residents by training in the latest standards of dementia care and by embracing their aspirations, creativity and ideas for a better life for residents

To improve the activity levels of residents with dementia, care staff must be adequately equipped to provide good quality dementia care. In our study we found that higher job demands as perceived by care staff strongly predicted residents' lower activity involvement. Over the years, several organizational strategies to reduce job demands and job strain have been proposed, such as according staff greater influence in making their own working schedules[63], giving them more decision authority[64], reconsidering time-consuming rules and regulations (which

the Dutch government is currently addressing)[63], or replacing working routines by the provision of person-centered care[65].

However, a first step in supporting care staff is acknowledging that caring for people with dementia is a complex job. Often, it is done by individuals with a low education level, and in some countries, by some who did not receive training in caring for people with dementia at all[66]. Providing good dementia care requires certain skills. These skills encompass having knowledge of the dementia syndrome, providing person-centered care, being able to make contact with residents, being a good observer, being able to deal with complex behavior, and being creative[1,66,67]. These skills must be trained when they are not yet present .

Care homes must teach staff to use activity provision to manage complex behavior or to make contact with people with severe dementia, instead of taking restrictive measures or feeling unable to comfort a person with severe dementia. This might increase their experienced working competence, which can protect them from job strain[68]. It might also make their work more meaningful. It is important to support initiatives that come from care staff, embrace staff's own creativity, let staff make their own choices in education programs so that they learn what they find of interest and what they are motivated for, and give staff room to learn from each other. Furthermore, management can support care staff by organizing regular meetings to discuss the behavior of residents with the care home's psychologist, and by facilitating peer supervision.

5.8 Proper staffing levels in care homes are essential for good care provision and need to be ensured. Therefore, care homes must evaluate their use of the available means

Job demands as experienced by care staff are at least partly caused by inadequate staffing levels, since these factors were correlated in this study. Both a higher staff ratio and a higher educational level of staff were related to greater activity involvement by people with dementia living in care homes. Although it was found that the quality of care did not entirely depend on the staffing levels within care homes[69], care managers cannot expect their care staff to provide activities to their residents, when they have to take care of 10 residents on their own for the best part of the day.

Based on the Quality framework that calls for more staff in dementia care homes, the Dutch Government has recently decided that from 2018, 435 million Euro will be made available to secure higher staffing levels in all care homes[70].

However, extra money will not be the full solution to the problem. In our study, we found considerable variation in staffing levels between care homes. Whereas the mean staffing level was 21 hours of staff per week per resident, the actual levels varied from 14 to 31 hours a week per resident. These differences are striking, since the care homes participating in this study were all state financed and delivered care to the same types of residents, and therefore received virtually equal governmental funding for each resident they cared for. Staff ratio and educational level were not found to be correlated, in other words, a higher staffing level was not compensated by a higher percentage of staff with a lower educational level. This indicates that other financial choices are responsible for the variation in staffing levels, for example overhead costs. This insight prompts an urgent call for care homes to look into the distribution of their financial means. A less hierarchical organization of the larger care providers and a reduction of overhead costs, might be a key factor in better allocation of the available means. This recommendation supports the conclusion of the Dutch Healthcare Authority, that also noticed a large variation in staffing levels, and called for the careful evaluation of the differences in spending the available means between care homes[71].

5.9 The care sector must restore a positive image of working in long-term dementia care

Working in long-term care for older people has acquired a negative image over the years. The work is relatively low paid and the career perspectives are limited. People work irregular hours and often there are no fulltime jobs available. This image as well as the working conditions must be improved, in order to attract and keep more workers in this sector. The 435 million Euro allocated by the Dutch government are meant to create 7,000 extra fulltime jobs, but many care homes already struggle to fill their current vacancies with equipped care staff[72]. Showing society that working in nursing home care also includes fulfilling the residents' need for activity involvement and thereby making time for making true contact and having fun with residents, will help restore the sector's image.

6. Implications for future research

Based on this study, we make the following recommendations for further research.

6.1 The maximum potential of activity involvement can best be studied with longitudinal research

In our study, we found that activity involvement and resident wellbeing were related, as measured at a single point in time. Our study does not provide evidence that 'regular activity involvement' or daily occupation also affects wellbeing or quality of life in the long run. Therefore, longitudinal research is needed.

Conducting longitudinal research among people with dementia is a complex task, due to the progressive nature of the dementia syndrome that can influence (bias) the results. Still, we argue for this kind of research, to obtain more insight into the effect of activity involvement on quality of life or wellbeing. The research would also shed light on the effects on cognition, functioning level and behavioral symptoms, as well as contact with the social environment, involvement of family members and volunteers, and family satisfaction and the mental health of informal caregivers. As stated in the Healthy Aging model of the WHO[12], it is important to look not only at the characteristics of a disease, but to also at how these characteristics interact with trajectories of functioning. Perhaps, with the right amount of occupation or with the right activities, the usual trajectory of deterioration due to the dementia syndrome can be mitigated.

A good example of a relatively small study on the effect of individually adjusted activities on quality of life is the Enriching Opportunities program, that was completed in the UK[15]. In this study, an intervention of increasing meaningful occupation in nursing home units with the regular care staff, was studied with a repeated measures within-subjects design. Both qualitative and quantitative data were collected for 127 residents at three points in time during a 12-month period, with a follow-up seven to 14 months later, demonstrating a positive impact of the program on wellbeing and a reduction in levels of depression. This type of research could lead to recommendations for care practice to implement such interventions.

6.2 Monitoring of care for people with dementia provided in care homes should be continued

In order to further improve nursing home care in the Netherlands for people with dementia, we strongly recommend that the Dutch government put more emphasis on monitoring research and making optimal use of the knowledge that has already been generated by several research institutes.

The LAD-study gave us the opportunity to monitor the developments in long-term dementia care in the Netherlands, and to study questions of policy makers as well as care practice, and provide recommendations. We found that when the Dutch government decided that care homes should cover a part of the financial costs themselves, many care homes stopped participating. At that time, care homes were asked to participate in other studies by other research teams as well, often with similar study aims.

Monitoring is extremely important in order evaluate all developments that take place in nursing home care for people with dementia. Examples are the introduction of the Quality Framework[42] and the extra financial means that the Dutch government has made available for both daily occupation and staff education[63]. Another example is the impact of the decreasing work force in dementia care due to the aging population and the increasing care demands of dementia care home residents. However, monitoring must be done efficiently, with the collaboration of various research institutes, to avoid collecting the same data with different instruments, and to make sure care practice can actually use the data that is collected (for example for accountability purposes), making it worthwhile for care homes to invest in participation.

With the 'Delta-plan for Dementia'[73] that was initiated in 2013, research institutes and care professionals are encouraged to work collectively on improvements in dementia care. However, the focus mainly lies on innovative research projects (such as alternative day care projects, use of new technological aids, studying the benefits of physical exercise programs, development of new programs for the support of informal caregivers), whereas we believe that it is also necessary to monitor current practice for providing recommendations for improvement.

6.3 Both the research field and care practice would benefit from further development of our instrument that uses staff observations for daily occupation and wellbeing

As described in chapter 5 of this thesis, we have used staff observations to derive information about the daily occupation of care home residents with dementia and their wellbeing. We believe that this instrument has the potential to adequately measure daily occupation and wellbeing on a large scale and should therefore be developed further.

Our study results when using this method were in line with previous research, although we did find several points for improvement concerning the description of the classification categories as well as the distinction between types of occupation. The instrument should also be tested for intra- and interrater reliability.

Whereas further development of the instrument may lead to a feasible alternative to collecting data, it could also be used to increase awareness among care staff of the effect of meaningful occupation on residents' wellbeing , and the actual level of wellbeing enhancing types of occupation with their own care practice. Currently, Dementia Care Mapping is increasingly used for this purpose[74]. Dementia Care Mapping is more complex in use however, and the observers must undergo thorough training. Our proposed alternative measure has the potential to be more feasible, and can be widely used in care practice.

6.4 The role of activity involvement as part of the impact of small-scale group living on resident wellbeing should be further investigated

In previous research, no strong evidence was found for the beneficial effect of small-scale group living home care on resident quality of life[17-19]. However, in this study, we found that small-scale care was related to higher activity involvement, and higher activity involvement was related to better quality of life. This implies that activity involvement might act as a mediating variable in the potential effect of group living home on quality of life. In other words, the effect of group living home care on quality of life might be determined by the extent to which the environmental stimuli and compensations for which the concept was intended[75], are actually used. Further research should point out if this assumption is correct.

6.5 Additional research on the role of family in enabling care home residents to continue to live a meaningful life is needed

It would be helpful to further study the role of family involvement and its impact on residents' wellbeing. The participation of family members in the care for their relative is a hot topic in dementia care practice. Besides the (politically driven) idea that family caregivers should contribute to daily care practice for financial reasons, in light of the aging population, it is increasingly recognized that family involvement is essential for other reasons. These include advocacy on behalf of the residents' needs and wishes, and providing the care home with information about a resident's life history and personal habits in order to enable person-centered care. Despite the availability of tools and shared experiences between care organizations[76], care homes still have difficulties with regard to increasing the involvement of and cooperation with family members. More in-depth research might contribute to solving this problem.

6.6 The determinants of job demands (or work pressure) among care staff need further exploration

An expected yet important result of this study, is the finding that the job demands as experienced by care staff are a key predictor of activity involvement. The experienced workload is determined by all kinds of factors, for example the physical and emotional care needs of residents, staffing levels, but also by support from colleagues and supervisors, and thoughts and feelings about the tasks that have to be executed and feelings of competence in this regard[66,77]. Examples of these thoughts and feelings that were found to result in limited activity provision to residents, are a conviction of being incapable of involving residents in activities[15,17], and a perceived lack of support from colleagues with regard to spending time on providing activities[28]. With the shrinking labor market in mind, it is essential to further explore the concept and determinants of experienced job demands among care staff, in order to make their work conditions more favorable, resulting in a beneficial influence on the wellbeing of residents.

6.7 The role and mechanism of good leadership in care practice should be studied

Inconsistent with the literature, the supervisor support perceived by care staff was found to be negatively, yet strongly, related to higher activity involvement. Based on the assumption that care staff would find themselves more supported in the choices they make, for example in spending time on interacting with residents, we did not expect to find a negative association. The same holds for transformational

leadership, since it stands for being a role model, being supportive, allowing room for staff's own creativity and being visionary[78]. Perhaps, if a supervisor is not activity-minded, supportive leadership might result in less activation than directive leadership by someone who strongly values activity provision to residents. Further research is needed to clarify the relationship between the role of leadership and activity involvement by residents.

Concluding remarks

When comparing with other countries, we realize that Dutch nursing home care is already of a high standard. This starts with the fact that in the Netherlands, people with dementia have access to long-term care. Together with Sweden, the Netherlands spends the highest percentage (3.5% in 2011) of gross domestic product on long-term care (including dementia care)[12], of all European countries. This number is likely to rise in 2018. Furthermore, as compared with most other countries, staff have received a higher level of education, especially in terms of their training in communicating with people with dementia[79].

However, also in the Netherlands there are large differences in quality between care homes[80]. The enormous variation in the quantity and education level of the available staff, as well as the variation in activity involvement found in this study, show that financial budgets are not the primary cause of low activity levels among people living in care homes.

In line with the Healthy Aging model of the WHO[12], care organizations have the task to maximize their residents' wellbeing by ensuring an optimal alignment between the residents' individual needs and the care environment. Today, several good practices show that this is possible. In order to make real change towards a better life for residents with dementia in care homes, it is time for care organizations to stop thinking that money is the sole cause of their problems, and take responsibility for the wellbeing of their residents within the available budgets. Let's make their lives worth living.

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Summary

Seize the day!

Chapter 1 is the general introduction to this thesis. There is increasing awareness of the potential influence of daily occupation and activity involvement on the wellbeing of people with dementia living in care homes. However, researchers consistently find a lack of activity involvement in care homes for people with dementia. This thesis addresses this anomaly.

Over the past decades, an immense transformation has taken place in nursing home care for people with dementia. Whereas until the 1970's, nursing home care had a mainly medical focus, seeing residents as patients who needed treatment in a hospital-like setting, it is now recognized that maximizing the residents' psychological wellbeing should be the center focus of the care and guidance that people living with dementia receive. 'Psychological wellbeing' is generally perceived as the most important component of quality of life, and has been described in terms of positive mood, happiness, enjoyment and satisfaction.

With the Healthy Aging model that was published in 2015, the World Health Organization (WHO) has explicitly called upon the care environment to take responsibility for people's wellbeing. The Healthy Aging model states that diseases such as depression, and geriatric syndromes like dementia, comorbidity and other health related factors do not determine the wellbeing of older people, rather the extent to which the reduction in capacities as a result of these diseases are, or are not, compensated by the environment.

In the Netherlands, small-scale group living home care has, for some time, been seen as an important way to influence wellbeing through the environment. With small-scale group living home care, residents live together in groups of 6 to 8, and receive care and guidance in a recognizable, home-like environment. Today, it is estimated that 20 to 30 percent of care homes are arranged in a group living home care manner. However, research has not produced convincing results pointing at a higher quality of life for residents of group living home facilities as compared to residents of traditional nursing home facilities. This anomaly has led to the insight that altering the physical environment does not necessarily generate high quality care as provided by care staff. Care that is focused on the fulfillment of psychological needs might play a more important role in maximizing the residents' wellbeing.

One of these basic human needs is engagement in life in a meaningful way, or meaningful occupation. People with dementia are increasingly less able to fulfill this need themselves, and must rely upon the social environment to involve them in daily activities.

While awareness has increased in the dementia care sector of the need for occupation, care homes generally do not yet seem to have succeeded in providing activities to an accepted level. This is often expressed by people with dementia and their representatives, and also reflected in the research. Activity provision is often perceived as a secondary task for care professionals. And activity programs and interventions as proposed in the literature, generally require a financial investment for implementation in care practice.

With this thesis, we have tried to provide more insight on this matter by studying the relationship between daily activity involvement and wellbeing, as well as the barriers and enabling factors regarding the provision of activities in care home settings. To generate this information, the following research questions were studied: 1) *To what extent are involvement in activities and daily occupation related to the quality of life and wellbeing of people with dementia living in care*

homes? Is this relationship different for people at varying stages of dementia? And 2) *Which characteristics concerning residents, environment and staff influence involvement in activities and daily occupation?*

Chapter 2 describes the overall design of the Living Arrangements for people with Dementia (LAD-)study. The LAD-study is an ongoing Monitor of developments in Dutch nursing home care for people with dementia, and of the consequences of environmental and organizational characteristics on the wellbeing of residents, family and staff. Data collection takes place every two years. The first measurement cycle of the LAD-study took place in 2008-2009, in which 136 care homes participated -representing different types of Dutch nursing home care. In the second measurement cycle (2010-2011), 144 care homes participated. Some of these homes were the same, and some different, from the first cycle. In the third measurement cycle in 2013-2014, 50 care homes were included. The in-depth study was performed in 2010 among 10 care homes that participated in the first measurement cycle, in order to gain more knowledge on the facilitators and barriers that determine good dementia care. In this study, data from all three measurement cycles were used, as well as data from the in-depth study.

In **chapter 3**, the daily occupation of care home residents with dementia was examined, as well as their levels of wellbeing when involved in different types of occupation. Data from the in-depth study were used (2010). For a period of six hours, Dementia Care Mapping observations were performed on 56 residents representing 10 care homes.
We found that reminiscence, leisure, expression, and vocational occupation seem to be of greater value for residents' wellbeing than other types of occupation. We labeled these types of occupation 'wellbeing-enhancing'. It must be noted that physical exercise, a type of occupation that is frequently found to positively influence wellbeing, did not occur during our observations. We found that the wellbeing-enhancing types of occupation were rarely offered. On average, residents were involved in wellbeing-enhancing occupation for less than 5% of the observed timeframes. There was considerable variation, however, between the participating care homes. Whereas the residents of one care home were engaged in wellbeing-enhancing occupation for 25% of the observed timeframes on average, this was only 1% for the residents of a second care home.
Care homes in which residents were regularly engaged in wellbeing-enhancing occupation more often had a homelike atmosphere, supported social interaction through the environment, and did not have a central activity program.
The findings express the need to evaluate the use of time in daily care practice. With the right types of occupation, one might reach higher levels of wellbeing among residents with dementia than is currently the case. An example would be to focus on reminiscence instead of the usual small talk.
In this study, staff ratio was not found to be clearly related to time spent in wellbeing enhancing occupation. This suggests that the occupation of residents depends on how care workers use the available time and how staff are equipped to engage residents in wellbeing-enhancing activities. Training on involving residents in occupation by using the stimuli that are (or should be) present in the residents' living environment might be a key answer to improving their wellbeing.

In **chapter 4**, our large-scale study on the relationship between duration of involvement in activities and different outcomes of quality of life is described. Data were obtained by structured observational questionnaires that were filled in by care staff in the period 2010-2011. For 1,144 residents representing 144 care homes, data on involvement in a wide range of activities and

quality of life were available.
It was found that, on average, residents were involved in activities for less than three hours during a three day period. For reliability reasons, listening to music, watching television and having a conversation were not included. There was much variation between individuals in duration of activity involvement: 38.8% of the residents were involved for less than one hour over three days (defined as low activity involvement); 30.2% were involved for one to three hours (medium activity involvement); and 31% for more than three hours (high activity involvement).
More activity involvement was related to higher outcomes of quality of life in terms of a better care relationship, higher positive affect, less restless behavior, better social relations, and more often having something to do. These results likewise applied to people with severe dementia.
Activity involvement also had negative outcomes. More activity involvement was related to lower positive self-image as compared with medium and low activity involvement. Furthermore, high activity involvement was related to more social isolation as compared with low activity involvement. This shows that activity provision is a complex task, and should be carefully adjusted to a resident's preferences and capabilities.
The sole contribution of activity involvement to residents' quality of life appeared to be relatively minor in this study - it explained a small amount of the difference in quality of life found between residents of the low, medium and high activity involvement groups. Nonetheless, our findings are promising, since overall, residents were involved in activities to only a limited extent. The 'involvement for over one hour a day' was defined as 'higher activity involvement'. It can be expected that if low activity involvement were compared with truly high activity involvement (for example involvement for four hours a day), the relative impact on quality of life would be much greater. The fact that activity involvement was related to several domains of quality of life, as proposed in several quality of life theories, illustrates the diverse impact and meaning it may have for someone's wellbeing.
The measurement instrument used in this study, the *Activity Pursuit Patterns*, proved to be difficult in practice, presumably because of its retrospective character. Owing to incomplete data, 17% of the resident sample could not be studied. In addition, care staff found it hard to discriminate passive from active activity involvement, with consequences for the validity and reliability of our study results.

In **chapter 5**, the level of occupation among care home residents with dementia and its relationship with wellbeing for these residents was studied once more, while taking their stage of dementia into account. Based on our experiences with the measurement instruments that were used in previous studies, a new observational method was applied as a potentially feasible alternative instrument for monitoring occupation in this study population. With this method, care staff members observed the occupation and wellbeing of two residents, during three work shifts. In total, 171 residents representing 50 care homes were observed in 2013-2014.
We found that various types of occupation were related to higher wellbeing. In the overall sample, the occupation types 'having visitors, playing games, physical exercise or sports, activity related to the past, and conversation' had the strongest relationship with wellbeing. Performing domestic tasks, creative activities and occupying the mind were also related to wellbeing but at a somewhat lower level.

Eating or drinking, and listening to music or watching TV only had a small positive correlation with wellbeing.
The relationship between types of occupation and wellbeing was found to vary amongst people at different stages of dementia. In those with very severe dementia, eating or drinking seemed to be more important for their wellbeing than in other groups. Activities related to the past were also of great importance in this resident group. Additionally, this group benefitted from looking around with attention, in other words, being passively involved. Having visitors was less important for this resident group in terms of wellbeing.
Our findings reveal the need for residents to stay in touch with their network, or with other persons who specifically come to visit them and give them personal attention, at least for those with mild to moderately-severe dementia. Our study also shows that active stimulation of residents with dementia is desirable. However, consistent with our previous research, the observed residents mainly spent their time in types of occupation that were not significantly linked to better wellbeing, which implies there is room for improvement.
The findings also show that different types of occupation are important for residents, depending on their stage of dementia, which underlines the importance of identifying the resident's functioning level. When the disease progresses, care staff and family must re-discover what types of occupation are suitable for the person with dementia and discuss how to organize these activities.
This study suggests that regular care staff seem able to observe their residents' occupation and wellbeing. Although there is a need to study its validity and reliability in more detail and to further fine-tune the different types of occupation, the instrument seems promising.

Chapter 6 contains a description of the relationship between small-scale group living home characteristics and involvement in activities in general, and activities that are specifically preferred by the resident. The study used a sample of 1,327 care home residents with dementia. These residents lived in 136 care homes that represented different types of nursing home care in the Netherlands and their data were collected in the first measurement cycle of the LAD-study (2009-2010).
A first indicator of small-scale group living home care was the care home's score on the Group living home care characteristics questionnaire, reflecting the implementation of typical features of group living home care (e.g.: living rooms have a homelike atmosphere, dinner is prepared in the kitchen of the living rooms, nursing staff do housekeeping, and residents can get out of bed whenever they want). Secondly, the number of residents at the total facility site was used as an indicator of small-scale care.
Residents of facilities with more group living home care characteristics were involved in more general as well as preferred activities. Furthermore, they were more often involved in task related activities, outdoor activities, leisure pursuits, physical exercise, and interaction with others. For the other types of activities (religion, creative activities, intellectual activities and activities involving the senses) no differences were found as compared to residents with fewer characteristics of group living home care.
The number of residents at the total facility site was not related to involvement in activities, except for the finding that residents of larger facilities were less involved in intellectual pursuits. The results appear to contradict the concerns that a strong focus on a normalized life, and the absence of a central activity program or specialized activity workers, lead to low activity levels among residents within small-scale care homes.
As a secondary finding, we discovered that neuropsychiatric problems and ADL dependency (needing more help with physical care, transferring, toileting and eating and drinking), as well as

the age and sex of residents were stronger predictors of activity involvement than the indicators of small-scale care. These findings indicate that older residents, male residents, residents with more challenging behavior and more ADL dependency should receive specific attention when it comes to activity involvement.

Chapter 7 explored the predictive value for activity involvement of several resident characteristics, resources in terms of finances and staff, care culture, staff experiences, the environment and activity offer. A sample of 1,218 residents representing 139 care homes was used, derived from the second measurement cycle (2010-2011) of the LAD-study.
Out of 40 factors that were studied, seven were identified as having the strongest relationship with higher activity involvement (defined as involvement for more than one hour a day). Higher activity involvement was predicted by: less agitated behavior, less ADL dependency and cognitive impairment, a higher educational level of staff, fewer perceived job demands and less social supervisor support, and a smaller number of residents in the facility. Factors that were also related to higher activity involvement, but proved to be of secondary importance, were: more involvement of family caregivers in the decisions and procedures in the care for their relative, greater unity in care philosophy among staff, more group living home care characteristics, and more help from volunteers at the facility, less transformational leadership, a higher staff ratio and not offering activities in the form of clubs.
The results imply that in order to increase the activity involvement of care home residents with dementia, it seems vital to 1. Reduce staff's experienced job demands, 2. Elevate their overall educational level, 3. Train staff to provide suitable activities considering the behavior and preserved capabilities of residents and 4. Foster transition towards small-scale care. In order to do so, care organizations might need to evaluate the use of their financial means.
Further research is needed to study the role of the supervisor in activity involvement of residents.

Chapter 8 contains the overall discussion of this thesis. In this chapter, the main findings are summarized and discussed. Furthermore, several implications for care practice, health policy and future research are described.

<u>Main study outcomes</u>
In our study, we consistently found that activity involvement is beneficial for the overall quality of life of care home residents with dementia. Residents who were more involved in activities had higher scores on several quality of life subscales, and their involvement in several types of daily occupation was related to higher wellbeing scores.
This conclusion can be drawn for people in all stages of dementia, although the correlation with activity involvement and quality of life was somewhat weaker for residents with very severe dementia, and somewhat different types of occupation were related to their wellbeing compared to residents with less advanced dementia.
Our observation of the types of daily occupation that residents were involved in revealed that certain types of daily occupation were related to higher wellbeing, and others were not. Having visitors, playing games and engaging in leisure activities, physical exercise, reminiscence activities, conversation and domestics tasks had the

largest impact on wellbeing. However, these 'wellbeing enhancing types of occupation' were not often observed.
Although there is much variation between and within care homes, overall it can be said that there is only occasional involvement of dementia care home residents in activities or wellbeing-enhancing types of occupation. This implies that there is much room for improvement in care homes.

Several factors were found to enhance or limit activity involvement or daily occupation. These facilitating and impeding factors should be referred to when attempting to improve activity involvement in care homes for people with dementia. First, disease-related characteristics of residents are strongly related to their level of activity involvement: residents who are more physically and cognitively impaired are generally less involved in activities. Second, a stimulating environment seems to increase the residents' involvement in activities and daily occupation. Characteristics of small-scale group living home care as well as fewer residents living in the care facility predicted higher activity involvement and were also related to more involvement in activities of preference of the resident. A home-like atmosphere and an environment that supports social interaction might contribute to more involvement in wellbeing-enhancing types of occupation. Third, factors relating to the manpower that is needed to provide activities for residents with dementia (a higher percentage of staff with educational level 3 or higher, less perceived job demands by staff, a higher staff ratio, more assistance from volunteers) are related to higher activity involvement. And finally, more involvement of relatives in decision making, a well implemented care philosophy, and less supervisor support and less transformational leadership were associated with higher activity involvement.

<u>Implications for care practice and health policy</u>
Based on our study findings, we have several recommendations for care practice and health policy.

- To increase the provision of activities in care homes, a change in perception of the content of nursing home care is needed. ***It should be recognized that involving residents in activities is just as vital for resident wellbeing as providing physical care.***

- Since activities should match the physical and cognitive abilities of a resident and also his or her interests, ***knowing the residents is a precondition for activity involvement that is aligned with the person's need.***

- Providing activities to residents with dementia during the day is not an easy task. Therefore, ***care staff must be taught what meaningful occupation entails, and how to integrate activity provision within their daily work.***

- Our findings show that the physical environment can contribute to activity involvement. ***Care homes should become a stimulating environment that lowers the threshold for staff to provide activities. Providing small-scale group living home care is a good starting point.***

- Having visitors is important for residents; family involvement in decision making is related to more activity involvement and family can provide information on a resident's life history, preferences and social network. Therefore, ***cooperation with family members is essential for residents to get the most out of their lives in the care home.***

- Care homes should embrace the potential of volunteers in activity provision. ***Since finding as well as keeping volunteers is challenging, care homes must discover their needs and motivation in order to get and keep them on board.***

- Today, people often move into care homes when they have complex care needs. To be able to offer these people activities besides providing physical care, ***care staff must receive training on the most recent care guidelines and evidence on dementia care. Furthermore, care managers should embrace their staff's aspirations, creativity and ideas for a better life for residents.***

- ***Proper staffing levels in care homes are essential for activity provision in the care home and need to be ensured.*** The large differences in staff ratio and educational levels between care homes, indicate that care organizations must evaluate their use of the available means.

- If more money becomes available for dementia care homes for the purpose of attracting more staff, ***the care sector must repair the negative image of long term dementia care.*** Showing society that working in nursing home care also includes fulfilling the residents' need for activity involvement and thereby making time for making true contact and contributing to the happiness and wellbeing of residents, will help in this process.

Suggestions for future research

The outcomes of this research, as well as our experiences with the data material and study design, led us to make the following suggestions for future research.

- In our study, we found that activity involvement and resident wellbeing were related, as measured at a single point in time. Our study does not provide evidence that activity involvement or daily occupation also affects wellbeing or quality of life in the long run. ***The maximum potential of activity involvement can best be studied with longitudinal research.***

- In order to further improve nursing home care in the Netherlands for people with dementia, ***we recommend that the Dutch government puts more emphasis on monitoring research and making optimal use of the knowledge that has already been generated by several research institutes.***

- As one of the instruments to measure daily occupation and wellbeing of residents with dementia, we used staff observations. ***Further development of this instrument may lead to a feasible alternative to collecting data, but also to increased awareness among care staff on this area.***

- ***The role of activity involvement as part of the impact of small-scale group living home on resident wellbeing should be further investigated.*** Based on our research, we hypothesize that the effect of group living home care on quality of life might be determined by the extent to which the environmental stimuli and compensations for which the concept was intended, are actually used.

- ***Additional research on the role of family in enabling care home residents to keep living a meaningful life is needed.*** This study points at the importance of family involvement. Despite the availability of tools and shared experiences between care organizations, care homes still have difficulties with regard to increasing the involvement of and cooperation with family members. More in-depth research might contribute to solving this problem.

- ***The determinants of job demands (or work pressure) among care staff need further exploration.*** Experienced job demands are not the sole result of staffing levels. Given the important impact on activity involvement of residents, it is vital to further explore what contributes to job demands, in order to combat this negative experience of care staff.

- Inconsistent with the literature, the supervisor support perceived by care staff was found to be negatively, yet strongly, related to higher activity involvement. ***Further research is needed to clarify the relationship between the role of leadership and activity involvement by residents.***

To conclude, activity provision should be recognized as a core element of the care for people with dementia living in care homes, even for those with severe dementia. When care homes succeed in finding ways to ensure proper staffing levels and equip their entire care staff with skills to integrate activity provision in their daily work, the wellbeing of residents at all stages of dementia can be improved. It is often thought that this is a matter of having enough financial resources. Best practices show us, however, that attention for activities is possible, even within the budgets that are currently available. Therefore, to make a real change, it is essential for care homes to recognize that money is not the sole cause of the problem, and that they must take responsibility for the activation of their residents.

Samenvatting

Seize the day!

Hoofdstuk 1 is de algemene introductie van dit proefschrift. Er is steeds meer aandacht voor het potentiële effect van dagelijkse bezigheden en betrokkenheid in activiteiten, op het welbevinden van mensen met dementie die in zorgvoorzieningen wonen. Uit onderzoek blijkt echter steeds weer dat deze mensen zeer weinig gestimuleerd worden. Deze tegenstrijdigheid vormde het uitganspunt voor dit proefschrift.

De afgelopen decennia heeft de verpleeghuiszorg voor mensen met dementie een enorme verandering doorgemaakt. Tot de zeventiger jaren had de verpleeghuiszorg een hoofdzakelijk medisch karakter. Bewoners van woonzorgvoorzieningen (toen nog echte *verpleeghuizen*) werden als patiënten gezien, die langdurig behandeld en verzorgd werden in een ziekenhuisachtige omgeving. Tegenwoordig is men overtuigd dat niet de medische behandeling maar het psychologische welbevinden van bewoners centraal moet staan in de geboden zorg en begeleiding van mensen met dementie in woonzorgvoorzieningen. 'Psychologisch welbevinden' wordt beschouwd als de belangrijkste component van kwaliteit van leven, en kan worden omschreven als 'een positieve stemming', 'geluk', 'tevredenheid', of 'blijheid'.

In 2015 publiceerde de Wereld Gezondheidsorganisatie (WHO) het Healthy Aging model. Hiermee riep de WHO de zorgomgeving expliciet op om verantwoordelijkheid te nemen voor het welbevinden van ouderen met gezondheidsproblemen. Het Healthy Aging model zet uiteen dat ziektes zoals depressie en geriatrische syndromen zoals dementie, comorbiditeit en andere gezondheidsgerelateerde factoren niet verantwoordelijk zijn voor een bepaalde staat van welbevinden van oudere mensen, maar dat het welbevinden afhangt van de mate waarin de beperkingen die samengaan met deze aandoeningen, wel of niet worden gecompenseerd door de omgeving.

In Nederland is het principe van kleinschalig wonen lange tijd gezien als dé manier om de beperkingen van mensen met dementie te compenseren middels de omgeving, en daarmee het welbevinden van deze mensen te optimaliseren. In kleinschalige woonvoorzieningen wonen bewoners samen in groepen van 6 tot 8 mensen, en worden zij verzorgd in een herkenbare en huiselijke omgeving. Naar schatting is tegenwoordig zo'n 20 tot 30 procent van de woonzorgvoorzieningen waar verpleeghuiszorg voor mensen met dementie wordt geboden, ingericht als kleinschalige woonvoorziening.

Onderzoek leverde echter geen bewijs op dat bewoners van deze woonvoorzieningen een betere kwaliteit van leven ervaren dan mensen met dementie die in traditionele verpleeghuizen wonen. Dit leidde tot het inzicht dat het veranderen van de fysieke omgeving niet automatisch resulteert in een hogere kwaliteit van de geboden zorg. Mogelijk speelt zorg die gericht is op het vervullen van psychologische behoeften van bewoners een belangrijker rol als het gaat om het optimaliseren van hun welbevinden.

Eén van deze psychologische behoeften is de menselijke basisbehoefte om een betekenisvol leven te leiden, of een betekenisvolle daginvulling te hebben. Mensen met dementie zijn steeds minder goed in staat om deze behoefte zelf te vervullen. Zij worden afhankelijk van de sociale omgeving om hen in dagelijkse bezigheden, of activiteiten, te betrekken.

Terwijl er steeds meer aandacht is voor een zinvolle dagbesteding in de dementiesector, lukt het woonzorgvoorzieningen over het algemeen nog maar slecht om bewoners regelmatig in activiteiten te betrekken. Dit gegeven wordt regelmatig met zorg geuit

door mensen met dementie en hun vertegenwoordigers, en is ook aangetoond in onderzoek. Het bieden van activiteiten wordt vaak gezien als een neventaak van zorgmedewerkers, de prioriteit ligt bij de lichamelijke verzorging. Succesvolle activiteitenprogramma's en interventies zoals beschreven in de literatuur brengen vaak hoge kosten met zich mee, en zie je maar weinig terug in de zorgpraktijk. Het lijkt daarom belangrijk om ons zoveel mogelijk te richten op de normale dagelijkse bezigheden van bewoners.
Dit proefschrift biedt meer inzicht in de genoemde problematiek, door de relatie tussen dagelijkse betrokkenheid in activiteiten en welzijn te bestuderen, alsmede de bevorderende en belemmerende factoren voor het bieden van activiteiten in woonzorgvoorzieningen. De volgende onderzoeksvragen stonden centraal:
1) *In welke mate is de betrokkenheid in activiteiten en dagelijkse bezigheden van invloed op de kwaliteit van leven en het welbevinden van mensen met dementie die in woonzorgvoorzieningen wonen? Is deze relatie anders voor mensen met verschillende stadia van dementie?* En 2) *Welke kenmerken van bewoners, de zorgomgeving, en zorgmedewerkers beïnvloeden hun betrokkenheid in activiteiten en dagelijkse bezigheden?*

In **hoofdstuk 2** is de algemene opzet van de Monitor Woonvormen Dementie beschreven. De MWD is een doorgaande monitor van ontwikkelingen in de Nederlandse verpleeghuiszorg voor mensen met dementie, en de gevolgen van omgevings- en organisatorische kenmerken op het welzijn van bewoners, familie en zorgmedewerkers. De gegevensverzameling vindt elke twee jaar plaats. De eerste meetronde vond plaats in 2008-2009. Destijds deden 136 woonzorgvoorzieningen mee, die verschillende typen verpleeghuiszorg vertegenwoordigden. In de tweede meetronde (201-2011) deden 144 woonzorgvoorzieningen mee. Een deel van deze huizen waren hetzelfde als in de eerste meetronde, het andere deel deed voor het eerst mee. In de derde meetronde (2013-2014) zijn 50 woonvoorzieningen onderzocht. In 2010 is een verdiepende studie uitgevoerd binnen 10 woonzorgvoorzieningen die meededen in de eerste meetronde, om meer kennis te vergaren over de bevorderende en belemmerende factoren voor goede dementiezorg. In dit proefschrift zijn gegevens van alle drie de meetronden van de MWD gebruikt, alsook de gegevens van de verdiepende studie.

In **hoofdstuk 3** zijn de dagelijkse bezigheden van bewoners van woonzorgvoorzieningen voor mensen met dementie onderzocht, en het welbevinden van deze bewoners op het moment zij betrokken waren in de verschillende typen bezigheden. Hiervoor zijn de gegevens van de verdiepende studie gebruikt (2010). Gedurende zes uur werden Dementia Care Mapping observaties gedaan in tien woonzorgvoorzieningen, waarbij in totaal 56 bewoners zijn geobserveerd.
We zagen dat reminiscentie-activiteiten (het ophalen van herinneringen), ontspanningsbezigheden, expressieve bezigheden, en het doen van huishoudelijke klusjes, meer bijdroegen aan het welzijn van bewoners dan andere typen bezigheden. We definieerden deze typen bezigheden dan ook als 'welzijnsbevorderende bezigheden'. Hierbij moet gezegd worden dat beweegactiviteiten, die in de literatuur vaak geassocieerd worden met hoger welbevinden, niet voorkwamen tijdens onze observaties.
De 'welzijnsbevorderende bezigheden' werden maar zelden aangeboden. Gemiddeld werden de bewoners in minder dan vijf procent van de geobserveerde tijdsintervallen in deze bezigheden betrokken. Er was echter veel variatie tussen de deelnemende woonvoorzieningen. Terwijl bewoners van de ene woonvoorziening in een kwart van de geobserveerde tijdsintervallen in welzijnsbevorderende bezigheden werden betrokken, werden bewoners van een andere woonvoorziening slechts in één procent van de tijdsintervallen in deze bezigheden betrokken.

Woonvoorzieningen waarin bewoners regelmatig in welzijnsbevorderende bezigheden waren betrokken, hadden vaker een huiselijke sfeer, ondersteunden de sociale interactie tussen bewoners middels de omgeving (bijvoorbeeld door de aanwezigheid van gezellige zitjes), en hadden geen centraal activiteitenprogramma maar boden activiteiten voornamelijk in de huiskamer aan.
De bevindingen laten zien dat het van belang is om stil te staan bij de invulling van de beschikbare tijd die zorgmedewerkers hebben in de dagelijkse zorgpraktijk. Wanneer men focust op de juiste bezigheden, kunnen wellicht hogere niveaus van welbevinden worden behaald dan nu het geval is. Bijvoorbeeld door in een gesprek heel gericht herinneringen van vroeger op te halen met een bewoner, in plaats van over koetjes en kalfjes te praten.
In deze studie zagen we niet dat de personele bezetting duidelijk gerelateerd was aan de tijd die bewoners betrokken waren in welzijnsbevorderende activiteiten. Dit impliceert dat de bezigheden van bewoners afhankelijk zijn van hoe de zorgmedewerkers de beschikbare tijd invullen, en in welke mate de medewerkers zijn toegerust om bewoners te betrekken in welzijnsgerelateerde activiteiten. Scholing over het betrekken van bewoners in passende bezigheden en het gebruik maken van de stimuli die aanwezig (zouden moeten) zijn in de woonzorgomgeving lijkt een belangrijk middel om het welbevinden van bewoners met dementie te vergroten.

In **hoofdstuk 4** is onze grootschalige studie naar de relatie tussen de tijd die bewoners betrokken waren in activiteiten en diverse uitkomsten van kwaliteit van leven beschreven. De gegevens van deze studie werden verzameld met gestructureerde observationele vragenlijsten die zijn ingevuld door verzorgenden in 2010-2011. Voor 1144 bewoners van in totaal 144 woonvoorzieningen waren complete gegevens over hun betrokkenheid in 20 soorten activiteiten en kwaliteit van leven beschikbaar.
We zagen dat bewoners gedurende drie dagen, gemiddeld minder dan drie uur in de diverse activiteiten betrokken waren. Hierbij is het luisteren naar muziek, tv kijken, en het hebben van een gesprek echter niet meegenomen. Wegens betrouwbaarheidsreden moesten deze activiteiten worden uitgesloten uit het onderzoek.
Er was veel variatie tussen de bewoners in hoe lang zij in activiteiten waren betrokken: 38.8% van de bewoners was minder dan één uur gedurende drie dagen in activiteiten betrokken (gedefinieerd als lage betrokkenheid), 30.2% was één tot drie uur in activiteiten betrokken (matige betrokkenheid), en 31% van de bewoners was meer dan drie uur gedurende drie dagen betrokken (hoge betrokkenheid).
Meer betrokkenheid in activiteiten was gerelateerd aan hogere uitkomsten op verschillende gebieden van kwaliteit van leven. Mensen die meer in activiteiten waren betrokken, hadden een betere zorgrelatie met de zorgmedewerkers, een hoger positief affect (betere stemming), minder rusteloos gedrag, betere sociale relaties, en konden zichzelf beter vermaken. Deze positieve relatie met kwaliteit van leven gold ook voor mensen met zeer ernstige dementie.
Betrokkenheid in activiteiten had ook negatieve uitkomsten. Bewoners met een hoge betrokkenheid in activiteiten hadden een lager positief zelfbeeld vergeleken met bewoners die matig, of weinig in activiteiten betrokken waren. Ook hadden bewoners met een hogere betrokkenheid in activiteiten, een hogere score op

sociale isolatie dan bewoners die weinig in activiteiten betrokken waren. Dit impliceert dat het bieden van activiteiten complex is, en dat activiteiten zorgvuldig aangepast moeten worden aan de voorkeuren en mogelijkheden van de bewoner.
De specifieke bijdrage van betrokkenheid in activiteiten aan de kwaliteit van leven van bewoners bleek relatief klein in dit onderzoek: slechts een beperkt deel van het verschil in kwaliteit van leven tussen bewoners kon worden verklaard door hun betrokkenheid in activiteiten. Toch bieden de bevindingen hoop, omdat de onderzochte bewoners over het algemeen maar zeer beperkt in activiteiten waren betrokken. 'Hogere betrokkenheid in activiteiten' werd gedefinieerd als 'betrokkenheid voor meer dan een uur per dag'. Het is te verwachten dat de impact van activiteiten op kwaliteit van leven veel groter is, wanneer lage betrokkenheid in activiteiten zou kunnen worden vergeleken met daadwerkelijk hoge betrokkenheid in activiteiten (bijvoorbeeld betrokkenheid in activiteiten voor ten minste vier uur per dag). Het feit dat betrokkenheid in activiteiten inderdaad is gerelateerd aan diverse domeinen van kwaliteit van leven, zoals al werd gesuggereerd in verschillende theorieën over kwaliteit van leven, laat de brede impact en betekenis van activiteiten voor iemands welbevinden zien.
Het meetinstrument dat in deze studie werd gebruikt, de *Activity Pursuit Patterns* (APP), bleek moeilijk in gebruik, waarschijnlijk door het retrospectieve karakter van de APP. Door incomplete gegevens op dit instrument kon 17% van de bewoners in onze dataset niet worden onderzocht. Bovendien zagen we dat zorgmedewerkers het moeilijk vonden om onderscheid te maken in passieve van actieve betrokkenheid in activiteiten. Dit heeft gevolgen voor de validiteit en betrouwbaarheid van onze studieresultaten.

In **hoofdstuk 5** zijn de dagelijkse bezigheden van bewoners van woonzorgvoorzieningen met dementie en de relatie met hun welbevinden opnieuw onderzocht. Ook hier werd rekening gehouden met het stadium van dementie waarin zij zich bevonden.
Gebaseerd op onze ervaringen met de meetinstrumenten die we gebruikten in eerder onderzoek, ontwikkelden we een nieuwe observatiemethode om de bezigheden in deze studiepopulatie eenvoudiger te kunnen monitoren. Volgens deze nieuwe methode observeerden dagelijkse zorgmedewerkers de bezigheden en het welbevinden van twee bewoners tijdens drie werkdiensten. In totaal zijn 171 bewoners van 50 woonzorgvoorzieningen geobserveerd, in 2013-2014.
In deze studie zagen we dat verschillende typen bezigheden gerelateerd waren aan een hoger welbevinden van bewoners. Over het algemeen hadden de bezigheden 'bezoek hebben, spelletjes doen, beweegactiviteiten, reminiscentie activiteiten, en gesprekken', de sterkste relatie met welbevinden. Huishoudelijke taken, creatieve activiteiten en intellectuele activiteiten waren ook gerelateerd aan welbevinden maar in mindere mate. Eten en drinken en het luisteren naar muziek of tv kijken hadden een zeer kleine positieve relatie met welbevinden.
De relatie tussen typen bezigheden en welbevinden verschilde tussen de groepen mensen met verschillende stadia van dementie. Bij mensen met zeer ernstige dementie was de bezigheid 'eten en drinken' belangrijker voor het welbevinden dan in de andere groepen. Reminiscentie-activiteiten waren ook heel belangrijk voor het welbevinden van de mensen met zeer ernstige dementie. Ook passieve betrokkenheid bij activiteiten, dat wil zeggen, geïnteresseerd naar activiteiten kijken, was belangrijk. In onze studie was het krijgen van bezoek bij deze subgroep niet gerelateerd aan een hoger welbevinden.
De bevindingen van deze studie wijzen op de behoefte van bewoners om in contact te blijven met hun netwerk, of andere mensen die hen speciaal komen bezoeken en persoonlijke aandacht bieden (in ieder geval voor mensen met milde tot matig-ernstige dementie). De resultaten laten ook zien dat actieve stimulatie wenselijk is. De geobserveerde bewoners besteedden hun

tijd echter met name aan bezigheden die niet gerelateerd waren aan een hoger welbevinden, zoals we ook vonden in eerder onderzoek. Hier is dus ruimte voor verbetering.
Uit de studie komt ook naar voren dat verschillende typen bezigheden belangrijk zijn voor bewoners in verschillende stadia van dementie. Dit benadrukt het belang van het hebben van kennis over de mogelijkheden en beperkingen van bewoners. Wanneer de ziekte voortschrijdt is essentieel dat de zorgmedewerker en familie opnieuw ontdekken welke bezigheden passend zijn, en dat zij met elkaar afstemmen hoe deze bezigheden kunnen worden georganiseerd.
Deze studie laat zien dat dagelijkse zorgmedewerkers in staat zijn om de betrokkenheid in bezigheden en het welbevinden van bewoners te observeren. Hoewel er meer onderzoek nodig is naar de validiteit en betrouwbaarheid van de observatie methode en er ook inhoudelijk verdere afstemming nodig is, lijkt het gebruikte meetinstrument veelbelovend.

Hoofdstuk 6 omvat de omschrijving van onze studie naar de relatie tussen kenmerken van het concept 'kleinschalige zorg' en de betrokkenheid in activiteiten in het algemeen, en ook betrokkenheid in activiteiten die de specifieke voorkeur hebben van de bewoner. In deze studie zijn gegevens van 1327 bewoners onderzocht. Deze bewoners woonden in 136 woonvoorzieningen, die de belangrijkste verschillende typen woonzorgvoorzieningen waar verpleeghuiszorg voor mensen met dementie wordt geboden vertegenwoordigden. De gegevens werden verzameld in de eerste meetronde van de MWD (2009-2010).
Een eerste indicator voor kleinschalige zorg was de score van de woonvoorziening op de *Vragenlijst kenmerken kleinschalig wonen*. Met deze vragenlijst wordt geïnventariseerd in hoeverre typische kenmerken van kleinschalig wonen (zoals 'de woonkamers hebben een huiselijke sfeer, maaltijden worden bereid in de keuken van de woonkamers, zorgmedewerkers doen ook huishoudelijke taken, en bewoners kunnen opstaan hoe laat zij willen') in de praktijk zijn geïmplementeerd. Als tweede indicator van kleinschalige zorg werd het totale bewonersaantal van de woonvoorziening gebruikt.
Bewoners van woonvoorzieningen met meer kenmerken van kleinschalige zorg, werden in meer typen algemene activiteiten, alsook in meer voorkeursactiviteiten betrokken. Zij werden met name meer betrokken bij huishoudelijke klusjes, uitstapjes, ontspanningsactiviteiten, beweegactiviteiten, en gesprekken. Er werden geen verschillen gevonden in de betrokkenheid in andere type activiteiten (religieuze, creatieve, of intellectuele activiteiten en zintuigstimulering) vergeleken met bewoners van woonvoorzieningen met minder kleinschalige zorgkenmerken.
Het totaal aantal bewoners van een woonzorgvoorziening was niet gerelateerd aan de betrokkenheid in activiteiten van bewoners, behalve dat bewoners van kleinere woonvoorzieningen vaker in intellectuele activiteiten werden betrokken.
De resultaten van dit onderzoek staan haaks op de soms geuite zorgen dat de grote nadruk op genormaliseerd wonen, en de afwezigheid van een centraal activiteitenprogramma en gespecialiseerde activiteitenbegeleiders, zou leiden tot minder betrokkenheid in activiteiten van bewoners van kleinschalige woonvormen.
Als secundaire bevinding zagen we dat onbegrepen gedrag, ADL- afhankelijkheid (d.w.z. meer hulp nodig hebben in de zelfzorg, het verplaatsen, eten en drinken en toiletgang), en de leeftijd en sekse van bewoners van grotere invloed waren

op betrokkenheid in activiteiten, dan de indicatoren van kleinschalige zorg. Dit impliceert dat oudere bewoners, mannelijke bewoners en bewoners met meer onbegrepen gedrag en ADL-afhankelijkheid, extra aandacht nodig hebben als het gaat om betrokkenheid in activiteiten.

In **hoofdstuk 7** is gekeken welke kenmerken van bewoners, de personele bezetting, de zorgcultuur, ervaringen van medewerkers, de omgeving en het activiteitenaanbod van invloed zijn op betrokkenheid in activiteiten. Dit is bekeken in een steekproef van 1218 bewoners, die 139 woonzorgvoorzieningen vertegenwoordigden. Deze steekproef kwam voort uit de tweede meetronde van de MWD (2010-2011).
Van 40 kenmerken die zijn bestudeerd, bleek er bij zeven een sterke relatie met een hogere betrokkenheid in activiteiten van verpleeghuisbewoners met dementie (gedefinieerd als betrokkenheid in activiteiten voor langer dan één uur per dag) te bestaan. Hogere betrokkenheid was gerelateerd aan: minder geagiteerd gedrag van bewoners, minder ADL-afhankelijkheid en minder cognitieve beperkingen, meer medewerkers met opleidingsniveau drie of hoger, minder ervaren werkdruk van medewerkers en minder sociale steun van de leidinggevende, en een kleiner bewonersaantal van de woonzorgvoorziening. Kenmerken die ook gerelateerd waren aan een hogere betrokkenheid in activiteiten, maar van secundair belang bleken, waren: meer betrokkenheid van mantelzorgers in de besluiten en procedures in de zorg voor hun naaste, meer eenduidigheid van medewerkers over wat de zorgvisie van een woonvoorziening in de praktijk betekent, meer kleinschalige zorgkenmerken, en een grotere inzet van vrijwilligers bij de woonvoorziening, minder transformationeel leiderschap, een grotere personele bezetting, en het niet organiseren van het activiteitenaanbod in de vorm van een verenigingsleven.
De resultaten van deze studie impliceren dat het voor het vergroten van de betrokkenheid in activiteiten van mensen met dementie die in woonvoorzieningen wonen, essentieel is om 1. de ervaren werkdruk van zorgmedewerkers te verminderen, 2. hun opleidingsniveau te verhogen, 3. zorgmedewerkers bij te scholen in het bieden van activiteiten die toegespitst zijn op het gedrag en de mogelijkheden van de bewoner, en 4. de verdere transitie naar kleinschalige zorg te faciliteren. Om dit mogelijk te maken moeten woonzorgvoorzieningen kritisch kijken naar hun gebruik van de beschikbare financiële middelen. Tot slot is er verder onderzoek nodig naar de rol van de leidinggevende in de betrokkenheid van activiteiten van bewoners, gezien de opmerkelijke resultaten hieromtrent.

Hoofdstuk 8 is de algemene discussie van dit proefschrift. In dit hoofdstuk worden de belangrijkste bevindingen samengevat en bediscussieerd. Daarnaast worden diverse aanbevelingen gedaan voor de zorgpraktijk, het gezondheidsbeleid en toekomstig onderzoek.

<u>Algemene uitkomsten van deze studie</u>
In dit proefschrift zagen we keer op keer dat betrokkenheid in activiteiten belangrijk is voor de algemene kwaliteit van leven van mensen met dementie die in woonzorgvoorzieningen wonen. Bewoners die meer in activiteiten waren betrokken hadden hogere scores op diverse subschalen van kwaliteit van leven, en hun betrokkenheid in verschillende typen dagelijkse bezigheden was gerelateerd aan hogere scores van welbevinden.
Deze conclusie kan worden getrokken voor mensen in alle stadia van dementie, hoewel de relatie tussen betrokkenheid in activiteiten en kwaliteit van leven wat zwakker was voor mensen met zeer ernstige dementie, en iets andere typen bezigheden gerelateerd waren aan hun welbevinden vergeleken met mensen die zich in een minder ver stadium van dementie bevinden.
Onze observaties van de dagelijkse bezigheden van bewoners toonden aan dat bepaalde bezigheden gerelateerd waren aan een hoger welbevinden, en andere bezigheden niet.

Bezoek krijgen, spelletjes doen, ontspanningsbezigheden, beweegactiviteiten, reminiscentie activiteiten, gesprekken, en huishoudelijke taken hadden de grootste relatie met welbevinden. Deze 'welzijnsbevorderende activiteiten' zijn echter niet vaak waargenomen.

Hoewel we grote verschillen zagen in betrokkenheidin bezigheden en activiteiten tussen én binnen woonzorgvoorzieningen, kunnen we over het algemeen zeggen dat mensen met dementie in woonzorgvoorzieningen maar af en toe in activiteiten of welzijnsbevorderende bezigheden worden betrokken. Hier is dus veel ruimte voor verbetering.

Diverse kenmerken in de zorgomgeving bevorderen of beperken betrokkenheid in activiteiten of dagelijkse bezigheden, die kunnen worden aangegrepen om de betrokkenheid te vergroten. Allereerst blijken ziekte-gerelateerde kenmerken van bewoners sterk gerelateerd aan een lagere betrokkenheid in activiteiten: bewoners met meer lichamelijke of cognitieve beperkingen zijn over het algemeen minder betrokken in activiteiten. Ten tweede lijkt een stimulerende omgeving de betrokkenheid in activiteiten en bezigheden te vergroten. Kenmerken van kleinschalig wonen en minder bewoners op een locatie hingen samen met een grotere betrokkenheid in activiteiten en waren ook gerelateerd aan meer betrokkenheid in de activiteiten van de specifieke voorkeur van de bewoner. Een huiselijke sfeer en een omgeving die de sociale interactie tussen bewoners stimuleert, draagt mogelijk bij aan meer betrokkenheid in welzijnsbevorderende bezigheden.

Ten derde dragen verschillende kenmerken van de personeelsinzet bij aan betrokkenheid in activiteiten van bewoners, namelijk een hoger percentage medewerkers met opleidingsniveau 3 of hoger, minder ervaren werkdruk, een hogere personeelsbezetting, en meer hulp van vrijwilligers. Verder hangen de betrokkenheid van familie bij de besluitvorming en een goed geïmplementeerde zorgvisie samen met een grotere betrokkenheid in activiteiten in een woonzorgvoorziening. Tot slot zagen we dat meer sociale steun van de leidinggevende en meer kenmerken van transformationeel leiderschap, juist zijn gerelateerd aan een lagere betrokkenheid in activiteiten.

<u>Implicaties voor zorgpraktijk en gezondheidsbeleid</u>

Op basis van onze bevindingen doen wij verschillende aanbevelingen voor de zorgpraktijk en het gezondheidsbeleid voor mensen met dementie.

- Om er daadwerkelijk voor te zorgen dat er in woonzorgvoorzieningen meer activiteiten worden geboden aan mensen met dementie, is er een omslag nodig in onze kijk op de inhoud van de verpleeghuiszorg. ***We moeten erkennen dat het betrekken van bewoners in activiteiten net zo belangrijk is voor hun welbevinden, als het bieden van lichamelijke zorg.***

- Omdat activiteiten bij de lichamelijke en cognitieve mogelijkheden én interesses van een bewoner moeten aansluiten, ***is het kennen van de bewoners een primaire voorwaarde voor betrokkenheid in activiteiten die zijn afgestemd op persoonlijke behoeften***

- Het bieden van activiteiten voor mensen met dementie gedurende de gehele dag is geen gemakkelijke taak. ***Daarom moeten zorgmedewerkers leren wat betekenisvolle activiteiten inhouden, en hoe zij het bieden van activiteiten kunnen integreren in hun dagelijks werk.***

- Onze bevinden laten zien dat de fysieke omgeving kan bijdragen aan betrokkenheid in activiteiten. ***Woonzorgvoorzieningen moeten dan ook een stimulerende omgeving vormen, om de drempel voor medewerkers om bewoners activiteiten aan te bieden te verkleinen. Het bieden van kleinschalige zorg is een goed vertrekpunt.***

- Het hebben van bezoek is belangrijk voor het welbevinden van bewoners, en betrokkenheid van familie in besluitvorming is gerelateerd aan meer betrokkenheid in activiteiten. Bovendien kan de familie belangrijke informatie leveren over de levensgeschiedenis, voorkeuren, en sociaal netwerk van een bewoner die nodig is voor betrokkenheid in activiteiten. ***Samenwerking met familie is dan ook essentieel voor bewoners om het meeste uit het leven in de woonzorgvoorziening te halen.***

- Woonzorgvoorzieningen zouden het potentieel van vrijwilligers voor het bieden van activiteiten meer moeten omarmen. Omdat het vinden én het behouden van vrijwilligers niet eenvoudig is, ***is het belangrijk dat woonzorgvoorzieningen zich verdiepen in de behoeften en motivatie van vrijwilligers om hen aan boord te krijgen en houden.***

- Vandaag de dag verhuizen mensen vaak pas naar een woonzorgvoorziening wanneer zij een complexe zorgbehoefte hebben. Om in staat te zijn om mensen met een grote geestelijke en lichamelijke zorgvraag ook voldoende in activiteiten te betrekken, moeten ***zorgmedewerkers geschoold worden in de meest recente richtlijnen en kennis over dementiezorg. Bovendien moeten zorgmanagers oog hebben voor de ambities, creativiteit en ideeën van hun medewerkers om zich in te zetten voor een beter leven voor bewoners.***

- ***Een voldoende personele bezetting is een voorwaarde voor het bieden van activiteiten binnen woonzorgvoorzieningen, en moet worden gewaarborgd.*** De grote verschillen in personele bezetting en opleidingsniveau tussen woonzorgvoorzieningen in dit onderzoek tonen aan dat zorgorganisaties kritisch moeten kijken naar het gebruik van de beschikbare middelen.

- Nu er meer geld beschikbaar komt voor woonzorgvoorzieningen voor mensen met dementie om meer personeel aan te trekken, ***moet de sector het negatieve imago van werken in de verpleeghuiszorg herstellen.*** Een startpunt is om de maatschappij te laten zien dat het werken in het verpleeghuis niet alleen maar gaat over de lichamelijke verzorging van mensen, maar juist ook gaat over het doen van activiteiten, en het maken van oprecht contact, waarmee het mogelijk is een verschil te maken in het welzijn van bewoners.

Aanbevelingen voor verder onderzoek

Op basis van de uitkomsten van dit onderzoek en onze ervaringen met de gegevensverzameling en studieopzet, doen wij de volgende aanbevelingen voor toekomstig onderzoek.

In onze studie vonden wij dat betrokkenheid in activiteiten en welbevinden met elkaar samen hingen. Dit hebben wij gemeten op een enkel punt in de tijd. Onze studie levert daarom geen bewijs dat betrokkenheid in activiteiten of dagelijkse bezigheden ook het welbevinden of de kwaliteit van leven op de langere termijn beïnvloedt. ***De maximale potentie van betrokkenheid in activiteiten kan het best worden onderzocht in longitudinaal onderzoek.***

- Om de Nederlandse verpleeghuiszorg voor mensen met dementie verder te verbeteren, adviseren we ***de Nederlandse overheid om meer nadruk te leggen op monitor-onderzoek en beter gebruik te maken van de kennis die al is vergaard door diverse onderzoeksinstituten.***

- Eén van de meetinstrumenten die wij gebruikten om dagelijkse bezigheden en het welbevinden van mensen met dementie in woonzorgvoorzieningen te meten, bestond uit een instrument waarbij verzorgenden de bewoners observeerden. ***Verdere ontwikkeling van dit instrument kan leiden tot een goed bruikbare methode om op grote schaal gegevens te verzamelen, en bovendien het bewustzijn op het gebied van activiteiten en welbevinden onder zorgmedewerkers te vergroten.***

- ***De rol van betrokkenheid in activiteiten als onderdeel van het effect van kleinschalig wonen op het welbevinden van bewoners zou verder onderzocht moeten worden.*** Op basis van ons onderzoek vermoeden we dat het effect van kleinschalig wonen op de kwaliteit van leven op zijn minst ten dele wordt bepaald door de mate waarin daadwerkelijk gebruik wordt gemaakt van de stimulerende en herkenbare omgeving zoals die oorspronkelijk was bedoeld.

- ***Aanvullend onderzoek is nodig naar de rol die familie heeft om bewoners in staat te stellen een betekenisvol leven te blijven leiden.*** Dit onderzoek wijst op het belang van familieparticipatie. Ondanks de beschikbaarheid van tools en gedeelde ervaringen tussen zorgorganisaties worstelen woonzorgvoorzieningen nog steeds om de betrokkenheid van en samenwerking met familieleden te vergroten. Meer verdiepend onderzoek kan eraan bijdragen dit probleem op te lossen.

- ***Er is aanvullend onderzoek nodig naar de determinanten van de ervaren werkdruk van zorgmedewerkers.*** Deze ervaren werkdruk is niet enkel het gevolg van een te lage personele bezetting. Gezien de impact op betrokkenheid in activiteiten van bewoners, is het raadzaam verder te onderzoeken wat nu bijdraagt aan ervaren werkdruk, als aanknopingspunt dit te verminderen.

- In tegenstelling tot wat in de literatuur is beschreven, vonden wij dat sociale steun van de leidinggevende als ervaren door zorgmedewerkers, en ook meer kenmerken van transformationeel leiderschap, samen hingen met een lagere

betrokkenheid in activiteiten. Wij kunnen enkel gissen naar de achterliggende reden hiervan. ***De rol en de werking van goed leiderschap in de zorgpraktijk vraagt dan ook nadere bestudering.***

Concluderend zou het bieden van activiteiten moeten worden gezien als een kernelement in de woonzorg voor mensen met dementie, ook als zij ernstige dementie hebben. Als het woonzorgvoorzieningen lukt om de aanwezigheid van voldoende personeel te waarborgen, en zij hun zorgmedewerkers vaardigheden bijbrengen om het bieden van activiteiten te integreren in het dagelijks werk, kan het welbevinden van bewoners in alle stadia van dementie daadwerkelijk worden vergroot. Vaak wordt gedacht dat dit een kwestie van geld is. Best practices laten echter zien dat voldoende aandacht voor activiteiten en betekenisvolle bezigheden nu al mogelijk is, binnen de beschikbare budgetten[i]. Om tot ware verandering te komen, is het voor woonzorgvoorzieningen dan ook van belang om te erkennen dat geld niet de enige oorzaak van het probleem is, en verantwoordelijkheid te nemen voor het activeren van hun bewoners.

[i] Ook vóór de tariefsverhoging van 2018 op basis van het Kwaliteitskader.

Appendices

Seize the day!

Dankwoord

Graag wil ik een aantal mensen speciaal bedanken voor hun bijdrage aan de totstandkoming van dit proefschrift.

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Dieneke

About the author

Dieneke Smit was born on April 13 1985 in Amsterdam, the Netherlands. She graduated from secondary school (Atheneum) at the Jac. P. Thijsse college in Castricum in 2003. Thereafter, she studied General Health Sciences at the VU university of Amsterdam. After receiving her Master's degree on Policy and Organization of Health care, she started working part-time as a research associate for the Program on Aging at the Netherlands Institute for Mental health and Addiction (Trimbos-insitute) in 2007. Here, she worked at the Living Arrangements for people with Dementia (LAD-)study. Next to her work as a researcher, Dieneke followed the European Masters of Gerontology at the VU university of Amsterdam, from which she graduated in 2009.

When studying Health Sciences, Dieneke got confronted with the disease process of her grandfather, who suffered from Alzheimer's disease. When he was admitted to a nursing home and got transferred to two other care homes thereafter, she experienced how the care environment could affect the wellbeing of people with dementia. Together with her father Henk, Dieneke got inspired to create an own care facility for people with dementia. In 2006, they wrote their first business plan for a 'small-scale care farm' for people with dementia, an alternative for the nursing home where residents would still find themselves in a stimulating environment, that would be aimed ad fulfilling their basic psychological needs as described in the person-centered care theory of Kitwood.

After 7 years of work, including internships in small-scale group living home care facilities, finding a cooperation with a social housing company, convincing the health insurance company as well as the local government and neighbors, and working as coordinator of the day care facility of colleague organization WarmThuis, the dream of Dieneke and Henk came true. In October 2013, they opened their care farm 'de Reigershoeve', for 27 residents with dementia. Since February 2014, also day care is provided.

Although Dieneke stopped as a research associate of the Trimbos-institute in October 2012 to become manager of De Reigershoeve, she picked up her study in 2014. She is married to Thijs and in 2015, she became mother of Jente.

Seize the day!

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